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THE SHADOW CAREGIVERS: AMERICAN FAMILIES AND LONG-TERM CARE

JOINT HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING
UNITED STATES SENATE

AND THE

U.S. BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE
(THE PEPPER COMMISSION)

ONE HUNDRED FIRST CONGRESS

FIRST SESSION

PHILADELPHIA, PA

NOVEMBER 13, 1989

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THE SHADOW CAREGIVERS: AMERICAN FAMILIES AND LONG-TERM CARE

MONDAY, NOVEMBER 13, 1989

U.S. Senate,
Special Committee on Aging,
and U.S. Bipartisan Commission on Comprehensive
Health Care (The Pepper Commission),
Philadelphia, PA.

The Special Committee on Aging/Pepper Commission hearing was held at the U.S. Courthouse, ceremonial courtroom, 601 Market St., Philadelphia, PA, Senator John Heinz, presiding.

Present: Senator Heinz and Commissioner James Balog.

Also present: Jeffrey R. Lewis, Republican staff director, Aging Committee; Steven C. Edelstein and Phil Shandler, professional staff, the Pepper Commission.

OPENING STATEMENT BY SENATOR JOHN HEINZ, PRESIDING

Senator Heinz. This hearing of the Pepper Commission will come to order.

Ladies and gentlemen, I want to introduce another member of the Pepper Commission who is here with me today, Jim Balog, who has probably been the most faithful attendee of our Pepper Commission meetings and hearings in Washington, DC and elsewhere, save for perhaps the Chairman, Jay Rockefeller. Senator Rockefeller, as you may know, replaced Claude Pepper, who passed away earlier this year. Claude is a much-missed dear friend and great advocate on behalf of many of the issues we will be discussing this morning.

I am going to yield to Jim in a moment for any comments he may wish to make, but I just want to explain briefly what the mission of the Pepper Commission is.

We have been charged by Congress with not one, but two very tall orders.

Order No. 1 is addressing the needs of the huge number of Americans, some 37 million of them, about one-third of them children, who do not have health insurance. These individuals are too well off for Medicaid, but do not have private health insurance.

Item No. 2 is the escalating need for long-term care services for the disabled, frail, or aged Americans.

By March 1990, that's just 4 months from now, our Commission has to deliver back to Congress a comprehensive solution to both of these serious and literally life-threatening inequities in our health-care delivery system.

Our job, however, does not end with drafting a blueprint and sending it off to engineering for implementation. Our job is to recommend how to fully finance the plan we send down and our job is also to make sure that whatever we recommend is sufficiently broadly drawn so that it can be enacted into law.

While the financing is going to be a challenge—it's going to take tens of billions of dollars of additional money—we need to find a solution that will not increase or exacerbate health care cost inflation.

I would like to see us eliminate what I believe is a two-tier system of health care protection. What may be a tall order, but I think the magnitude of the task only underscores the multitude of families and individuals in need.

If you look around Philadelphia or Pennsylvania or this country at our health-care system, what you find is both shocking and deplorable. What you find is that in one of the world's wealthiest countries, millions of individuals don't have any health insurance whatsoever.

If you look behind that statistic, you find families who are faced with the Hobson's choice of food and/or housing instead of medical care. So, they put off going to the doctor; they get very sick; they may get a cancer that could have been treated; they become terribly ill or even die because of a lack of health care.

Too often, in other words, the emergency could have been avoided. Instead, what we find in emergency rooms around the country is a child with a very high fever, perhaps pneumonia, who should have been treated earlier for a cold, sitting beside a gunshot wound victim.

An equally unacceptable scenario is the aged or disabled person who is wheeled through the door of a nursing home because the community services needed are either unavailable or unaffordable; it's not covered by either a Federal program or a private insurance program.

As you know, millions of aged or disabled Americans are in need of long-term care. Amazingly, most receive some help, but often it is at a staggering human cost or with frightening, financial, or emotional difficulties for either themselves or their caregivers.

We're going to hear today from some of the faces behind those statistics. We're going to hear, in particular, from what I call the shadow caregivers, those who too often are the unrecognized but critical bastions of support for millions of Americans with a chronic disorder.

They will tell us about the gaps in our health-care system, how those gaps often stifle choice, strip away human dignity, and shatter a lifetime of financial planning or force families to split apart to qualify for assistance.

Before I yield to Jim Balog, I just want to make one other observation:

As somebody who back in 1974 established the House Committee on Aging, I believe the debate about long-term care has been very long on talk and very short on results. I think I speak for my colleagues on the Pepper Commission and on the Senate Committee on Aging, on which I'm privileged to serve as ranking member, when I say that we intend to achieve a solution, one that tears down the constrictions of a two-tier health-care delivery system and promotes self-reliance, independence, dignity and, importantly, the family caregivers.

Enacting legislation isn't going to be easy because the place I work, the Congress, the Senate and House, is currently what you might call snake-bit. The snake was called Medicare catastrophic coverage and it bit real hard. In the next few days Congress is going to be making a decision that I can best characterize as whether to go into full retreat or simply surrender on the issue of Medicare catastrophic.

Our biggest challenge, therefore, in the Commission and for our colleagues, is to prove that the issues we're talking about here today are issues that must be addressed not only from a health-care policy point of view, but from a political point of view. They are also issues of the heart in that they deeply affect the lives of virtually every American family, if not right now, then in the future. They are indeed issues of critical public policy, but they are issues fundamentally of human decency.

So, I am confident that large as the challenges may be, tall as those orders are when piled up, one on the other on our plate, we can handle them and produce something that everyone can be proud of.

At this point, I would like to yield to Jim Balog and thank him once again for being here.

STATEMENT OF JAMES BALOG, COMMISSIONER

Commissioner Balog. Thank you, Senator Heinz, and good morning, ladies and gentlemen.

It's a real pleasure for me to be here since I'm returning to my native State. I was actually married in Philadelphia 40 years ago. So, it's a great pleasure to be here. I came from western Pennsylvania, out near Johnstown; so, Philadelphia was a long, long way away from where I grew up, but at any rate, I'm pleased to call both sides of Pennsylvania my home, one place where I was born and the other where I got married.

I am a Presidential appointee on this Commission. As you probably know, there are six Senators, six Congressmen and three Presidential appointees, of which I am one.

I might say that based on 10 years of participating in public health and in health policy in this country, I am most impressed with the distinguished Members of Congress who serve on this Commission, not the least of which is Senator Heinz. These are really expert people in the field of health-care policy, doing, I think, a very good job of trying to deal with the very complex problem Senator Heinz mentioned, health-care access and long-term care.

These kinds of hearings are very valuable in gaining information from you all in the grass roots who deal with these problems every day.

If I may, Mr. Chairman, I'd like to make three points to this audience at this time:

The first is that questions posed to witnesses necessarily imply what I'm thinking about. What I'm trying to do, most of all, is get the best of your brains, the best of your experience. So, my questions may be off in a different direction simply to get at what you know so we can learn as much as possible.

The second thing I would like to point out is that health-care costs and the total health-care problem is like a balloon. As I heard Senator Heinz say at one of our hearings in Washington, it's a balloon you squeeze in one place; it pops out somewhere else; you squeeze it there and it pops out somewhere else. It's a continuum; it's a very delicately balanced problem we're dealing with. So, it's not a simple matter of pushing in one place and having the solution come out at the other end.

The third point I'd like to make is that in the area of health care, the Government gives nothing. The Government collects from one group of people and distributes benefits to another and that's all it does, and in the process, hopefully, we create a system that eliminates waste, that's as efficient as possible, but in the final analysis, it's the shift of income from one group for use by another group.

Part of what we have to try to do, is to balance off all these various interests on the input side and output side.

Our 15-member Commission is very well aware of the enormous complexity and the urgent need represented in the matter of health-care policy and as Senator Heinz has pointed out, it's a matter of the head and heart.

I think we keep trying to put those two things together, the head in the practical matters of public policy and the heart with the kinds of problems we're dealing with. These aren't your ordinary kinds of problems that Government faces. These are very heart-felt problems, I think.

Our Commission and the congressional leadership is very distinguished, but in the final analysis, we are ordinary men and women dealing with an extraordinary problem.

We thank all of you for helping to bring us your views and your experiences so that perhaps throughout all of this we can make the best possible decisions both of the head and of the heart.

Thank you very much.

Senator HEINZ. Jim, thank you very much.

I know that it wouldn't have been necessary for you to both be from Johnstown and marry here in Philadelphia in order to get you here today, but we're nonetheless grateful.

When I say that this man is one of the most thoughtful and probing people on the Commission, I know he will not let us down in his questions here today. But before I call on our first witness, I do want to thank a number of people who are in the audience:

First and foremost, the Long-Term Care Campaign; second, the Action Alliance; and third, a lot of other people who I won't be able to mention who helped put our hearing together today. Your help was utterly invaluable and we're all deeply indebted to you and, indeed, I don't think we would have been able to find many of our witnesses without your help.

So, it's a special pleasure to begin today with our witnesses.

I'm going to start with Jack Armstrong, a famous name, and, Jack, thank you very much for whatever lengths you've gone to, to be with us here today.

Please proceed with your testimony.

STATEMENT OF JACK ARMSTRONG, ALS PATIENT, WYNCOTE, PA

JACK ARMSTRONG. My name is Jack Armstrong and I live in the Wyncote section of Montgomery County, right outside of Philadelphia. I am 38 years old and I've been married for 13 years. I have two daughters, ages 5 and 8. My profession is in human services. I'm currently a case-management supervisor for older adult services with a large private nonprofit social service agency in Philadelphia.

Approximately, 2½ years ago, I began to undergo tests through my general practitioner's office to determine the reason for muscle weakness that I was experiencing in my right leg. An examination by a podiatrist and subsequently a neurologist revealed that I was experiencing symptoms of a motor neuron disease that threatened my life. More extensive tests eliminated other possible causations, such as a pinched nerve or toxic poisoning.

In the spring of 1988, the diagnosis was confirmed, ALS, amyotrophic lateral sclerosis, commonly referred to as Lou Gehrig's disease.

By the time the diagnosis was confirmed, the muscle weakness was affecting my entire leg and I was then fitted for a leg brace. I was referred to the ALS clinic at Hahnemann University Hospital where I continue to be evaluated and monitored to this very day.

ALS, I learned, is a disease which disrupts one's ability to use muscles due to a deterioration of pathways connecting nerves to muscle. In many instances, those afflicted experience loss of use of muscles in the extremities and in the body trunk while others experience loss of the ability to speak, swallow and breathe; still, others are double blessed and experience both of these kinds of symptoms simultaneously.

In my particular situation, the progression of the disease has caused a continuum of adjustments to increased weakness in my right arm and both legs. I have become gradually more dependent on others for ambulation assistance, starting with a cane and a leg brace, then a walker, and finally a wheelchair, for my legs can no longer support my weight.

Being faced with such a scenario tends to dramatically alter one's outlook on life and can cause a family unspeakable anguish.

I needed to assess many aspects of my daily living needs with much support from my family, friends, and myriad of professional support services that I now needed to negotiate with.

My desire was to continue to control as many aspects of my life as possible, including home life as well as my job.

One obstacle that I faced was gaining entry into my home and having access to the first-floor bathroom facilities. Through the support of my extended family, I was able to have our home equipped with a ramp for a wheelchair and a handicapped accessible bathroom at an expense that exceeded $22,000.

I have maintained a strong desire to maintain full-time employment for as long as possible and have made use of many resources to assist me in that endeavor.

I am currently renting through my health insurance an electric wheelchair that enables me to navigate throughout my office building which fortunately is at street level. The longevity of this arrangement is really uncertain at this time.

Another area of concern which caused anxiety was transportation to and from work in a wheelchair. As I began to evaluate options, I discovered that by crossing the county line separating Philadelphia from Montgomery County, I was ineligible for either Paratransit or the Montgomery County Handicapped Transportation Services. Fortunately, the ALS Association has acquired a van with a wheelchair lift which has been most responsive to my situation and has enabled me to continue to travel to work.

At the present moment, although my wife, who is my primary caregiver, is struggling to maintain stability of our whole family, we seem to be coping only through the support of many caring friends, as well as support systems offered to the families of ALS patients.

A growing fear that I experience is the uncertainty of the future.

How much longer will I be able to work; what provisions exist to support my wife as the primary wageearner; what type of care will I need and what resources exist to provide it?

In reviewing the benefits of my health insurance plan which appears to be rather comprehensive, I am left feeling uncertain as to long-term benefits, particularly related to in-home nursing and unskilled personal care.

In the event I am unable to resume work, I anticipate receiving a portion of my salary as a disability benefit; however, I more than likely will need to pay privately for continuation of my health benefits which at the present time are quoted at about $350 a month.

Another concern facing us is affordable in-home care during the day while my wife is at work. Assistance with dressing, bathing, and meal preparation are nonreimbursable in most health insurance plans.

Finally, in the event it becomes impossible for my care to be provided at home, what type of affordable nursing care are available and at what cost?

An irony that strikes me through this struggle is that, for years, I have been working with families in my profession who are experiencing great stress and frustration as they ponder decisions concerning long-term care needs of their elderly loved ones. The families facing that scenario encounter a care system that's fragmented, inefficient, and inadequate to meet the total needs of frail, older adults. In my contact with other ALS patients, it is clear that the same problems exist across the age spectrum.

I am continually learning more about the dimensions of this problem we are addressing today and I really appreciate the opportunity to express some of my sentiments.

Senator HEINZ. Jack, thank you for that extremely thoughtful and valuable testimony.

Joyce Singer, would you be next, please?

STATEMENT OF JOYCE SINGER, YORK, PA

Joyce Singer. My name is Joyce Singer and I live in York, PA. In February 1987, I divorced my husband of 15 years, Michael Singer, to protect what few assets we had and to assure him proper medical assistance.

Mike suffered a massive cerebral hemorrhage almost 6 years ago which rendered him cognitively impaired and in need of custodial care.

Since the hemorrhage was not the result of an accident, he was not eligible for workmen's compensation or benefits available through the CAT fund.

Early in the morning of January 10, 1984, Michael had excruciating pain in his head. I rushed him to the hospital along with our daughters, then ages 9 and 13. After hours of surgery, he was placed in the intensive care unit where he remained in a coma and on life support for 7½ weeks. He developed numerous life-threatening complications and several times I was told he would not survive.

Mike improved and was eventually transferred to the Rehab Hospital of York. After 6 months, the hospital could no longer document improvement. Since our insurance would not cover plateau periods, discharge was a forced issue.

With discharge imminent, I began searching for home care for Mike since he couldn't be left unattended and required much help. It was necessary for me to work full time since we had no income beyond his Social Security Disability.

I quickly learned that home care was an unaffordable option. At $7 per hour for a home-care assistant, it would have cost $1,120 per month just to cover 8 hours a day, 5 days a week, the hours I had to work.

The next alternative was admission to a nursing home. Because of Mike's condition and our income, he qualified for skilled care under medical assistance which covered the difference between his Social Security Disability and the cost of the home. As with private insurance, medical assistance only pays for skilled care as long as progress is taking place. At the end of 1 year, Mike had shown no additional improvement and his medical assistance coverage ended.

Luckily, the first personal care home had just opened in York, the cost of which exceeded Mike's Social Security disability by only $300 a month. In addition to the lower cost, it seemed a more appropriate environment than a nursing home where most residents were old, ill, and close to death.

Mike's parents and I agreed to split the $300 out-of-pocket cost for the personal care home.

Mike remained there for 1 year until his urinary incontinence and bowel problems became too burdensome for the home and I was urged to find other accommodations.

We then moved him to another personal care home where he stayed for 2 years until the same problems forced his exit.

We now have Mike in a boarding home. Although the cost of living there is low, his disability payments cover the cost.

Conditions in the boarding home are far worse than they were in the personal care homes. There is much impatience with Mike's urinary and bowel problems and with his cognitive impairments. I am at times concerned with this safety. His placement there is inappropriate, but there is no alternative.

Michael's Social Security Disability is currently $792 a month or $26.04 per day to cover housing, food, clothing, eye care, dental bills, medications and medical expenses. This is below the Federal poverty level; yet, it is too high to qualify him for a Medical Assistance card.

Currently, Mike's parents handle most of the care-giving tasks not provided by the boarding home, such as driving him to the doctor, dentist, and barber, handling his Social Security paperwork and doing his laundry.

Our daughters and I try to provide emotional support for him by having him home on Sunday and including him in get-togethers.

Mike is 43 years old and can be expected to live a normal lifespan. His parents are in their 70's. They cannot assume this burden forever.

Our daughters are now 14 and 18 and it is difficult to imagine them assuming these responsibilities for quite a number of years.

I am already taxed beyond my limits, both emotionally and financially, from struggling with this situation for the past 6 years.

I am concerned that Mike will end up like so many others, just being shifted from one substandard boarding home to another.

We are not asking for welfare, but rather that affordable and appropriate help be given those who survive trauma. Society has provided the technical means for life to be sustained, but no means for survival in the aftermath. The current health-care system leaves the disabled and their families struggling to survive.

Mike is a college graduate. He held a dignified responsible job as a sales representative and was a loving, good father. As a responsible taxpaying citizen, he gave much to his country.

Today, he is left with no avenues of help to live with his condition, other than the quality of life that $26.04 per day will buy.

Senator HEINZ. Joyce, thank you very much for that story.

I know it was not easy for you to come and tell it to us, but thank you very very much for being here.

Terry Idelson would you be next, please?

STATEMENT OF TERRY IDELSON, PHILADELPHIA, PA

TERRY IDELSON. My name is Terry Idelson and I hope you'll bear with me; I'm very nervous giving this testimony, but I have learned to do a lot of things in the past 2 years that I never thought I would have to do.

Stephanie is my 2-year-old daughter. She was born on November 5, 1987, at our local hospital. Due to very floppy muscle tone and her inability to feed, Stephanie was transferred to the intensive care nursery at Mercy Medical Hospital shortly after birth.

Although various tests were performed, the doctors were not able to completely diagnose Steph until a few months later.

She was finally diagnosed as having Miller-Dieker Syndrome which is a very rare syndrome. It involves the brain. Her brain is not completely formed. For the most part, we were told to expect seizure problems, numerous pneumonias, severe mental and physical disabilities.

Stephie is now 2 years old and is functioning on a level of a 4-month-old baby.

During the first year, Stephanie was periodically hospitalized for seizure activity. At 8 months of age, her seizures were totally out of control. With each seizure, she was turning navy blue from head to toe.

During this hospitalization, tests also showed that Stephanie had central and obstructive apnea. The central apnea means that her brain forgets to tell her to breathe; the obstructive apnea means the muscle tone in her neck is so weak that her tracha simply collapses.

She also had chronic aspiration and reflux. Her food was going straight from her mouth into her lungs or from her stomach back up and into her lungs.

She also had fluid build-up on the brain.

After becoming stabilized on additional seizure medications during this hospitalization, Stephanie had a VP shunt surgically placed in an effort to relieve the pressure off her brain. The shunt is a tube which runs from her brain into her abdomen and drains the fluid off.

She then came home on continuous tube feedings and an apnea monitor.

In January of this year, Stephanie had her first pneumonia. It resolved fairly well, but a second pneumonia quickly set in in March. Within 24 hours of her hospitalization, Stephanie was in respiratory distress.

Since this was a life-threatening pneumonia, her recovery was much harder.

In addition to her medical equipment already at home, Stephanie now needed suction equipment, oxygen, and breathing treatments every 4 hours.

It was at this time I realized I could no longer do everything by myself. However, our insurance company denied our request for home nursing.

Family Help, our nursing agency, appealed the decision for us, but we received less than half of the nursing care we asked for; 20 hours a week was the nursing care we were given. It might seem like a lot of nursing care to some, but to me it meant I had 20 hours a week to clean house, do laundry, cook meals, run errands, go grocery shopping, take care of my 4-year-old, and do the things that a normal family usually does.

My husband was working between 50 and 70 hours per week with some of his work days being 17-hours long. Therefore, he was not able to be home to give me breaks during the day.

In an effort to simplify Steph's care, we planned to have a permanent feeding tube surgically placed. Unfortunately, when Stephanie was hospitalized for this surgery, our insurance company used this as an excuse to cut off all of our nursing care. They said that home nursing was supposed to help prevent hospitalizations. It did not matter to them that this was a one-time surgery planned in advance that would simplify Stephanie's care at home.

So, we went to Stephanie's secondary insurance company, HMA. She has HMA through her SSI, which incidentally, she was turned down for SSI twice and it took us 1 year to get her approved for SSI. Their excuse was that she was not severely disabled. However, HMA also turned us down.

I then went to Congressman Foglietta's office and asked for their help. We had 1 week to find alternate funding. With their help and a lot of work from Family Help, we were granted 24 hours of nursing care a week.

Unfortunately, Stephanie has now had three more pneumonias since August of this year. The worst of them was in September when Stephanie was on 80-percent oxygen or higher for 7 days. During this time, she received breathing treatments every 2 hours. It was touch and go for several days, but Stephanie finally improved and after 16 days of hospitalization, we had to prepare for her increased need in her level of medical care at home. She would be coming home on oxygen, six medications, tube feedings from 3 p.m. to 8:30 a.m. and breathing treatments every 4 hours around the clock. This basically meant that at night, I would do a breathing treatment, sleep 3 hours, do a breathing treatment, sleep 3 hours, et cetera, because each treatment takes a minimum of 45 minutes.

Also, this is Stephanie's baseline treatment. If she were to become sick, a simple cold, she would need treatments as frequently as every 2 hours.

I immediately called Family Help and they contacted HMA to request more nursing care.

Based on her current medical needs, HMA approved 8 hours a day of nursing care. I do the other 16 hours a day of nursing care. If I became sick, there's no one to take care of Stephanie during those 16 hours.

Although this helps us now, we know there will come a time when we'll need more nursing care for our daughter. She's not a child who will some day get well. We live on a day-to-day basis. Stephanie's medical care is expected to become more complicated, not easier.

In the meantime, we just try to hold on and live as normal a life as our circumstances will allow and pray that Stephanie will be with us tomorrow.

The sad part is every time Stephanie goes back to Children's Hospital, I see another mom and another child who are in exactly the same shoes as us.

Thank you.

Senator Heinz. Ms. Idelson, thank you very much. That is a tremendous story of heroism and it also leaves a lot of serious policy problems that we'll get into in a minute.

Let me call on Miriam Burnett.

STATEMENT OF MIRIAM BURNETT, PHILADELPHIA, PA

Miriam Burnett. Senator Heinz, Mr. Balog, please allow me to thank you for inviting me to testify before this Commission today on a subject that has had a grave impact on my life.

My name is Mariam Burnett and I'm an active caregiver for my 76-year-old mother who is a victim of Alzheimer's disease. Alzheimer's is a progressive and irreversible disease which gradually diminishes the victim.

My mother's case was diagnosed about 7 years ago, but I'm now convinced she displayed symptoms for 5 to 10 years prior to the diagnosis.

In that period, she was urged to retire from her career as a Government employee and eased out of positions of responsibility in her church and community.

As Alzheimer's disease progresses, the victim's loss of judgment, sense of time, and loss of powers of reasoning makes care increasingly more demanding.

My stepfather found himself assuming the role of homemaker in addition to coping with the enormous emotional burden of this devastating illness.

For me, the demand of care became a dilemma of splitting my emotional and physical energies between my job as a grade school teacher and my concerns for my parents. I had to take time off more and more frequently to assist with my mother's care.

My stepfather was old and in fragile health himself and the stress became increasingly unmanageable.

The time came when I knew we could not do it all alone and I began to investigate adult day care centers in my area. The closest one had a very long list. There was another one, but it did not provide transportation which meant I would have to lengthen my day on both ends to take my mother and pick her up at this center and here I was, trying to make life smoother.

Next, I considered home services, but the cost and the intrusion of privacy made them unacceptable in my mind.

For almost a year, I debated what to do and finally decided I would have to give up teaching. This was not an easy decision for me, but as an only child and considering the alternative of bringing a stranger full time into my parents' home or institutionalizing my mother, it was a decision I had to make.

During that year, the disease had progressed rapidly. Even without a job, I had to accept the fact that some outside help was mandatory.

Luckily, a new adult day care center opened with no waiting list and I was able to arrange for mother to attend 3 days a week.

At that time, I began staying at my parents' home on the evening preceding day care to help mother with her personal care. So, I spent 3 nights at mother's and 4 nights at my home with homemaking responsibilities at each.

My stepfather passed away this past July, after years of coping with a disease that was to him probably mystifying.

I spend night and day at mother's and I get to spend 1 night a week at my home.

My husband now has become a secondary victim of this disease. He either comes and eats with us or he cooks at home for himself. He does the laundry and the housekeeping and tries to keep up my spirits.

The effect of my mother's illness on my household has been dramatic. Our roles have been completely reversed, my mother's and mine. I now dress and undress her. I toilet her at regular intervals and I prepare her for going to day care and at this point, she calls me "Mama."

Fortunately, through my church family, I have been able to call upon some members for relief and some have even volunteered their help.

Mother has Medicare and Blue Cross/Blue Shield from her Government retirement, but they don't pay for services for Alzheimer's unless there's another accompanying physical disability which requires skilled care.

Only two times in the last year have I left my mother; once, when my daughter was having a baby, I went to North Carolina for 2 weeks, and then my husband and I took a week another time for ourselves. Both times, I had to put mother in a nursing home at the cost of $100 a day with no reimbursement.

If a person gives years of service to society, society should have a way of supporting that person in need without robbing him or her of their dignity. Families should not have to endure lengthy hassles to get private assistance and, like my mother, jeopardize their entire financial future to pay for them. The Government should assume the responsibility to fund and administer a broader program of long-term care. It should include a plan for affordable long-term care insurance which allows families to plan for the future with less trepidation. We also need better coverage for respite care.

As a family member, I'm grateful that this Commission exists and I implore you to persist until a satisfactory, humane solution is found.

In a country that acknowledges one nation under God, I end with this thought:

In so much as you have done it to the least of these, you have done it unto God.

Thank you for your attention.

Senator HEINZ. Ms. Burnett, you are still a great teacher.

MARIAM BURNETT. Thank you.

Senator HEINZ. As our last witness on this panel, I call on Christina Rodgers. Christina, thank you for being here.

STATEMENT OF CHRISTINA RODGERS, HERSHEY, PA

Ms. RODGERS. Thank you, Senator Heinz, Congressman Balog.

My name is Christina Rodgers and I want to thank you for inviting me to testify here today.

On September 8, 1976, when I was 38 years old, a man approached me in a parking lot of a shopping mall near Harrisburg. He forced me to get in my car, then shot me pointblank in my left breast, hoping to hit my heart, drove me to a deserted area where he raped me, dumped me in a field and left me for dead.

Sixteen hours later, a couple out walking their dog heard my scream. I was rushed to the Hershey Medical Center where they operated to try to correct the damage done to my liver and pancreas. I was already paralyzed by the bullet lodged against my spine. They couldn't get the bullet out. It is still there today.

I had been a registered nurse since 1958, a graduate of the Thomas Jefferson University, and had just been promoted to the nurse recruiter position at the Hershey Medical Center, a desk job. This was fortunate for me because I was able to return to work in my wheelchair in May 1977.

In 1984, I had to undergo major bowel surgery due to the adhesions that had resulted from my original injuries. At one point, the doctors thought I would never eat by mouth again.

In the next 2 years, I was in and out of hospitals many times with bills totaling $500,000 until April 1986 when I was told my insurance ran out. You cannot imagine the humility and despondency which this added to my handicap.

I come from an Irish Catholic family with eight children. My father was a proud man, he was a mailman, who taught us the value of paying your own bills.

My social worker said I needed to go on Medical Assistance, that all my possessions, including my car, would be confiscated.

I was terrified. My goal was to return to work as I said I had done back in 1977, but my physical condition worsened; so, I applied for disability benefits under Medicare. This meant a 2-year wait during which time I had to endure more hospital stays.

Without the professional courtesy of some of the doctors who treated me and waived or reduced their fee and the generosity of my family, I would be much deeper in debt today than I am. I still pay a modest sum each month on my five figure hospital bill. I dread seeing that bill in the mail each month as the balance never seems to get smaller.

So, on August 21, 1987, I got my Medicare card. I now get $697 from Social Security each month and have qualified for some home-care services under the Pennsylvania Attendance Care Program which is a demonstration program set up under the Department of Public Welfare.

At least one social worker and some doctors have suggested I give up my apartment and go into a nursing home.

I spent 28 days in a nursing home in 1986 which I had to pay for in cash since I had no insurance at that time. My condition is terminal, but I want to be out with people, not in a nursing home.

A large majority of those in need of care wish to remain in their homes, their treasured environment. They have neighbors close at hand, family members to run errands, preventing them from being hidden away in a nursing home. We need to make it easier to live at home through excellent caregiving, to preserve their dignity, sense of security, not to mention good health.

I know I will need care for the rest of my life. I am concerned about how I will pay for it. I'm also concerned that if I have to be dependent on another person for help that that caregiver be qualified and competent and have a sense of dignity for themselves as well as the person for whom they are caring.

In my full statement, I talk in greater detail about what constitutes a caregiver and I hope the Commission will take this in consideration as it reviews this hearing.

It is an honor to have met you, Senator. I thank you for continuing this campaign begun by your great predecessor, the Honorable

Claude Pepper. May all of his dreams for those of us in need of caregiving come true. That is my wish.

Thank you for your kind attention.

Senator HEINZ. Thank you, Ms. Rodgers.

I know that Jim Balog and I have over the years heard other instances of similar kinds of problems, but I don't think I ever have heard a more compelling and comprehensive case that illustrates how every member of an affected family, whether it is the individual himself in the case of Jack Armstrong and Ms. Rodgers or whether it is one of the caregivers, like Ms. Idelson, Ms. Burnett, or Ms. Singer, goes to heroic lengths to maintain not only the well-being of themselves or their loved one, but to maintain that special sense of independence and dignity.

Every one of you has wanted to get by without a hand-out. You've gone to incredible lengths to do so.

Where there have been occasional opportunities for help, which has been more than needed, each of you encountered a patchwork quilt of long-term care services which is actually more patch than quilt. More often than not it let cold air blow in on you and you didn't know whether you were going to freeze to death and die or not. I commend each and every one of you for giving us this very clear picture of what real life is like.

One of the issues we have to cope with in the Commission is how to design a long-term care system that meets the kinds of needs that you've described.

I have some individual questions for each of you.

I'll just start with Jack Armstrong and work my way down the table here.

What would be the one or two most important things that we on the Commission should insist on as we design what you might call a long-term care benefit package?

Jack.

JACK ARMSTRONG. I, myself, feel I would like to remain with my family as long as possible. That means as I continue, probably, to deteriorate, I would like to have some assurance that there's going to be an affordable type of skilled and competent in-home care that is going to be able to meet my needs and allow my wife to continue as normal a life as possible and not cause us financial catastrophe.

Senator HEINZ. So, your first priority is, obviously, in-home care.

To what extent is that going to be necessarily very skilled care? It will probably be fairly skilled at some point?

JACK ARMSTRONG. Right.

Senator HEINZ. But the need will change over time, too?

JACK ARMSTRONG. Yes.

Senator HEINZ. So, it will have to be flexible?

JACK ARMSTRONG. That's right.

Senator HEINZ. Who should be making the judgment about the kind of care you'll need? Do you have a doctor you would trust?

JACK ARMSTRONG. That's right; I would trust the doctors that treat me at the clinic that I attend to determine what type of care I should have.

Senator HEINZ. Ms. Singer, let's take the case of your husband. By the way, I gather that you are one of those people who got a divorce literally to protect their loved ones, all the members of the family?

JOYCE SINGER. Yes.

Senator HEINZ. It may seem incredible to people that in this day and age that because you get no help, you literally may have to divorce the person you love in order to take care of him.

What about you, Ms. Singer; what do you think is most needed? Is it basically pretty much what Mr. Armstrong suggested?

JOYCE SINGER. Yes, I agree with him on that.

My particular immediate concern and interest is for kinds of affordable and appropriate long-term care for brain-injured folks like my husband. He is one of many who are surviving today who wouldn't have in the past because of modern medical technology.

There are many programs available for some other groups of people. I'm sure that there are also shortcomings there, but for instance, there are group home situations for the mentally retarded. That type of situation would be very good for people like my husband, also, but he doesn't qualify for any of those programs because, first of all, you have to have a primary diagnosis of mental retardation and that diagnosis has to have had an onset before the age of 18 to even qualify for any of those programs.

So, I think there needs to be a lot of attention given to those kinds of long-term care and vocational opportunities for the brain injured segment of the population as well.

Senator HEINZ. You've described a tragic irony; in a sense, as your husband got sicker, he was moved to a lower and, therefore, less appropriate level of care.

How is it that the personal care home was unable to provide the level of care he needed?

JOYCE SINGER. It wasn't necessarily that they couldn't provide the level of care he needed.

Personal care homes generally want you to be totally independent. Urinary incontinence and bowel problems are something they don't particularly like to contend with. Generally speaking, they prefer to have the older retired person who really has very few medical problems and can pretty much be self-sufficient.

In some ways, Mike met that criteria, but certainly has a lot of deficiencies that doesn't make him quite exactly the cat's meow there.

Senator HEINZ. There was no way you could take care of your husband at home, I gather, under the circumstances.

JOYCE SINGER. No; he has a lot of short-term memory loss and he thinks that his capabilities are much greater than they are.

For instance, he would probably try to make himself something to eat and if he got distracted at all, he would leave the stove and forget that it was on.

There are many, many problems. It would just be impossible for him to be left alone unattended.

Senator HEINZ. If you didn't have to work, you might be able to cope, but you have to work to support your daughters?

JOYCE SINGER. Absolutely. I'm working two jobs.

Senator HEINZ. What you pointed out is that skilled nursing care is very unavailable unless you're showing consistent improvement and then the next level of institutional care is the boarding home?

JOYCE SINGER. Right.

Senator HEINZ. Which in Pennsylvania, for all our faults, is probably a better quality boarding home since we passed a State act, I think it was last year, to monitor quality.

Does that suggest we need something between those two?

JOYCE SINGER. Yes, something between those two that is affordable.

Senator HEINZ. Maybe a boarding home where, in fact, home health care or some skilled care can come into such a facility?

JOYCE SINGER. Yes.

Those things do exist, but they are not real affordable for the average person.

Senator HEINZ. Very well.

Ms. Idelson, what would you say we should most remember?

TERRY IDELSON. I think for my part, it would be some assurance that my nursing care would not be cut off tomorrow. I have no assurance, whatsoever, that they will not say that Stephanie should be put into a home because we cannot keep up the level of care at home.

Paying for the medical equipment at home may be as costly as putting her in an institution, but the fact is that I'm willing to do 16 hours a day of nursing care. I have to have some breaks, though. I have to have some sleep, but just knowing that I won't lose the nursing care in the next week or two and that I won't have to be fighting it every step of the way for the rest of Stephanie's life.

Senator HEINZ. What does HMA stand for?

TERRY IDELSON. Health Management Alternatives that took over for Health Pass.

Senator HEINZ. Health Pass was the insurance company that cut off your insurance because of the hospitalization?

TERRY IDELSON. No, that was my husband's private insurance.

Senator HEINZ. Private insurance?

TERRY IDELSON. Yes.

Senator HEINZ. Did you ever argue with that insurance company about——

TERRY IDELSON. Oh, yes; we've definitely argued with them.

If you call and mention my daughter's name, they basically want to hang the phone up on you.

She has now used all her insurance coverage for 1989 and will not have any more until January, but they've been very unreasonable.

Senator HEINZ. What company was that; do you mind telling me?

TERRY IDELSON. It's a union, Local 56.

Senator HEINZ. All right.

Ms. Burnett, what should we be sure to design into any program that would be responsive?

You've mentioned respite care, adult day care.

Is that what you think we should focus on from your standpoint particularly?

MIRIAM BURNETT. Right; from my perspective, I feel that is an important feature for an Alzheimer's patient and for the caregiver who wants to keep the patient at home for the longest period of time. The caregiver should be able to find some affordable day care; day care with longer hours that would be more flexible to the working person. It is not necessary in my case, but it should be available for a working person who would need respite in the way of adult day care after work and for weekends. It would be especially helpful for those kinds of times when they have to take care of personal business. I think respite care, affordable and more available to the caregiver, is important so that the caregiver can care for themselves and, therefore, be able to keep the person home for a longer time. They would be able to give them better quality care for a longer time if they could take some breaks and be able to afford it.

Senator HEINZ. If the Medicare Catastrophic Coverage Act isn't repealed in its entirety, there is a very modest respite care benefit that will be made available. I forget whether the benefit is 8 hours or 16 hours a week, but it is in-home.

The AUDIENCE. 80 hours a year.

Senator HEINZ. 80 hours a year; that's right.

The AUDIENCE. One-and-a-half hours a week.

Senator HEINZ. Thank you very much.

You mentioned that you did not feel comfortable having people come into your home.

MIRIAM BURNETT. At that point.

Senator HEINZ. At that point?

MIRIAM BURNETT. At an earlier point when my mother was not as advanced as she is now and I think I felt a lot more protective of her.

I am now aware of what the care means and how demanding it is and I'd be grateful for anyone to come in.

I think that the intrusion on her privacy situation is not as important to me now as it was then.

Senator HEINZ. Do you feel that with the adult day care you now have, roughly 8 hours a day——

MIRIAM BURNETT. Right; she's in 3 days a week.

Senator HEINZ [continuing]. Is that sufficient for you to get by?

MIRIAM BURNETT. It's not sufficient.

It's certainly a big help because I do get a chance to take care of some personal business and household chores while she's there. When she's home, I'm not able to do much of anything because it means I am watching her and caring for her at all times.

Senator HEINZ. What do you think about in-home respite care; would that be helpful?

MIRIAM BURNETT. That would be helpful, yes.

Senator HEINZ. Obviously, I'm familiar with the facility at Pennsylvania Hospital.

MIRIAM BURNETT. Right.

Senator HEINZ. Which is absolutely first rate. It has all the medical support and monitoring that anybody would ever want, plus some very caring people, a full staff and volunteers.

MIRIAM BURNETT. I have found that to be the case, but with adult day care, as with everything else, they can't manage everything.

So, I'm quite concerned that the point is going to come very soon when my mother's behavior and her care will be more than they can take care of at the adult day care.

Now I'm faced with what's going to happen once she's no longer appropriate for adult day care? That may not be too far in the future.

Senator HEINZ. You used a term in your testimony; you referred to your husband as a secondary victim.

MIRIAM BURNETT. Right.

Senator HEINZ. You described him as getting by all by himself. Could you elaborate a little bit more on what has happened to both him and you?

MIRIAM BURNETT. Well, in my testimony, I said that since my stepfather's death, I'm no longer living at home. I am now living with my mother and taking care of her which is in North Philadelphia. We live in West Philadelphia. I have chosen not to take her away from her familiar surroundings.

My husband comes by for dinner. He still has other obligations that he has to fulfill. When he's not able to come by and visit us for dinner—he has to fend for himself at home.

Since I am now at my mother's 6 nights and 7 days each week, I am no longer able to take care of the household chores at home. Consequently, he has to take care of our home while I take care of my parents and their home.

I consider him a secondary victim because he is affected by the kind of day I have with mother. My mood can ruin an entire day for him. He has to expend a lot of energy trying to keep me uplifted. He often agrees to change his schedule to stay with mother for me, for a short period or take care of an obligation because I can't leave mother.

Senator HEINZ. Come over to support you as you're supporting your mother?

MIRIAM BURNETT. Right.

Senator HEINZ. Ms. Rodgers, your tale is one of somebody who has done everything they could to remain independent, to get back to work; you worked for 7 years. I gather you're still struggling.

If you could get back to work, you would, but you have had a series of operations, I gather, between 1984 and 1986 that must have been overwhelming?

CHRISTINA RODGERS. Yes.

Senator HEINZ. Could you tell us how that 2-year wait for disability and Medicare affected your sense of well-being, independence, dignity, whatever you want to call it? Was that a particularly threatening time or were there worse times?

CHRISTINA RODGERS. I believe that was a very frightening time. In fact, it was the worst time because I lost control and when one human being loses controls, then there is a breakdown in the mind, body, and soul, and I'm sure my health deteriorated in those two years because of that.

Senator HEINZ. From our point of view, therefore, what should we do?

CHRISTINA ROGERS. Well, as a registered nurse, as you know, I was a member—I am having the Attendant Care Program come in several days a week, 11½ hours I'm allowed to have.

I had a home caregiver for 12 months. She unfortunately became ill and had to have surgery.

So, since April, I've been having hit and miss caregivers which have been people who I do believe are just passing through the night and are not qualified or competent in some of these agencies.

My concern is that we start in the nursing schools and in the medical schools to make sure that there is some monitoring of control and dignity to the recipient.

I have been at a loss at many times with people I've only had one day and had to dismiss them. They were not interested and that does make you feel very, very undignified; you do lose all that privacy and it does hinder the stability of the help.

The reason I'm here today is because of the 12 months of continuity.

So, in your recruiting, I would emphasize to the Commission that you would teach and train a caregiver who wants to be a caregiver and also have them give dignity to the patient, as well as they, themselves, should be dignified and feel good about themselves.

Now, I know that is going to increase with money and I realize that, but my feelings are, yes, they do affect the health of the patient which might have been at a good level and can be diminished.

In those 2 years, it wasn't as much as myself as it was the family. The family had to go through the painful 1976 incident and then those 2 years.

I have been a single unmarried lady. I have had lots of insurance preparing for my days when I would be able to enjoy a good retirement. Those days are no longer in the future, but I do emphasize good recruiting, good training, and a good level of standard of care in all agencies of each State.

Senator HEINZ. Hopefully, that is an issue that our next panel which includes some very critical providers might also address and touch on.

Thank you, Ms. Rodgers.

Let me call on Jim Balog.

Jim.

Commissioner BALOG. Thank you, Senator. There is one line of questions I would like to try out on you.

What we have seen is that long-term care is not what lots of people think it is, something for older people. We have had long-term care needs expressed here for someone 2 years old and people in their 30's, 40's, and 70's. It's a need of people of all ages and I think that's a dramatic idea that comes across from this panel.

The second thing is that the caregivers in these situations are mostly women. I've noticed this in many areas where we have taken testimony—that it's a particular burden on the female population because they seem to wind up providing the care.

The third observation I would make is that the system we now have which we call Medicare is really a Medicure system.

If you're in to be cured for something, it does a reasonable job, particularly if you're over 65.

What is doesn't do very well is provide care.

It's really a Medicure system instead of Medicare.

So what we're looking at here is some way to get care for those long-term conditions that may have started out as an acute medical problem, but have turned into a care problem, and it seems to me that it has to be graduated because these situations are all different, as you can see.

We can't say, let's provide nursing homes. Nursing homes are good for certain things. I'm convinced that most people don't want to go to a nursing home. Most people want to stay in their home and provide the health care.

The AUDIENCE. Right.

Commissioner BALOG. So, I can tell you that my perspective on long-term care will start with what can we do in the home where the patients are the happiest and the families are the happiest and yet where the least amount of the Nation's help goes?

Now, my question is, and I've gotten some of the answers from your testimony, along the lines of private insurance versus public plans, from what I've gathered here, perhaps with the exception of Mr. Armstrong, is that in most private plans, you dropped off the cliff sooner or later.

Your plan I guess works because you're still employed?

JACK ARMSTRONG. Right.

Commissioner BALOG. What would happen to you if you lost your employment?

You mentioned that is something you worry about.

Would you be able to convert to an individual plan if you didn't have your group plan?

JACK ARMSTRONG. I could, but the cost is about $350 a month. If I tried to continue on my own and pay for the coverage I have right now, I would estimate it would be about $350 a month.

Commissioner BALOG. Would anybody care to comment on the general notion, because some of you had private plans throughout these episodes that you experienced, what could they have done? Could they have, in fact, provided the benefits and coverage and financial assistance you needed or do you think that the system simply wouldn't accommodate a crisis such as you've experienced?

CHRISTINA RODGERS. Well, there's always a maximum.

With my plan, while I was fully employed, there was a maximum benefit of $500,000 and when I reached that, then that was dropped.

So, we pursued it, but that was it.

Commissioner BALOG. Yours was a plan, I guess, that was sponsored by a hospital, itself?

CHRISTINA RODGERS. Oh, Yes; that was Penn State University, Prudential.

Commissioner BALOG. Does anyone else want to comment on the adequacy or inadequacy of private coverage?

I noticed in Ms. Burnett's testimony she said that there should be a plan for affordable long-term care insurance which allows families to plan for the future with less trepidation.

It is feasible to have a plan?

MIRIAM BURNETT. It's feasible.

Commissioner BALOG. It would be very costly.

MIRIAM BURNETT. Right; that's the problem. The cost becomes prohibitive for folks to be able to do that.

I think if we could have insurance that would be paid for by society, that would be shared by all, then everyone could get the benefits at a lower, more affordable rate.

Commissioner **Balog**. In fact, the note I made for myself is that most of the plans you are all in are relatively small groups of people and one catastrophic loss like this bankrupts the plan, and I suppose then you get thrown out so the other people can continue the plan, to put it very bluntly.

So, what we need is a larger group to spread these, catastropic problems over larger groups and you're really talking about a public plan or public insurance.

You're saying if it was a large enough group, the premiums were low enough, and you could afford this kind of long-term care, you would be willing to pay the premium to get it?

Miriam Burnett. I'm sure people would.

Commissioner **Balog**. Do you want to say something, Terry?

Terry Idelson. My husband's insurance is a union and they always have this idea that the union stands behind their employees, but they do not.

With one of my daugther's pneumonias, she was hospitalized for 16 days. We were trying to get nursing care for home bound that would help me do the care that she needed at home. It's impossible to do 24 hours a day. If we had that established before, we could have shortened that hospitalization, and these hospitalizations at Children's Hospital are extremely expensive.

Whereas we spent all of our money this year with her being in the hospital, we could have spread it out over further periods of time if we had more nursing care at home.

Her last hospitalization was only 5 days because we had nursing care established at home and I knew I could bring her home sooner.

So, if we had had this established sooner, earlier in the year, we could have cut her hospitalizations down.

Commissioner **Balog**. Thank you very much.

Senator Heinz, I'm finished with my questioning.

Senator **Heinz**. Does anybody have anything else they want to add that you think we should have asked you about?

If you don't, I've got a question for you.

The **Audience**. Over here.

Senator **Heinz**. No, no, no; these are our witnesses.

I don't think we can quite handle the other 300 or 400 witnesses. Come to one of my town meetings. I'll be glad to call on you, but I've got another panel coming in from all different places.

Let me ask you this: I was doing a little math on the back of an envelope the other day and it turns out that if everybody in the United States was willing to take about a $50 bite a month out of their paycheck, and maybe we could split it with the employer the way we do with Social Security, we would generate about $60 billion a year to provide health coverage for the uninsured and provide long-term care services. But the question is: If you think back a few years before you all got into the difficulties that you did, what would have been your reaction to some politician who comes along and says, you know, you're making $700 or $800 a month; we're just going to take another $50 out of your pay check; what would you say to that fellow?

Jack Armstrong. Well, I might consider it if I had some assurance of what that money was going to get me.

Senator HEINZ. So, being as objective as you can be before you got ALS, you think you would have been at least objective enough to say, "What are we going to get for the money and is it going to be well spent"?

JACK ARMSTRONG. Yes.

Senator HEINZ. What do you think, Ms. Singer?

JOYCE SINGER. I guess that's my concern as well.

It's kind of hard to go back now and think how I might have reacted prior to all of this if you had said that.

I suspect that most people wouldn't react real well though if they hadn't gone through the situation, but I, too, like Jack would want some kind of assurance of what that was going to provide. I guess I would be a little bit afraid that maybe I would be paying that and still not see the help that my particular person needs, but it seems like one way of approaching it.

Senator HEINZ. Any other comments on that?

Ms. Burnett?

MIRIAM BURNETT. Thinking back prior to my situation, with all the deductions you have from your salary just anyhow, you generally get the feeling that you are well covered and you don't foresee any catastrophe coming down the line.

We're just not realistic about that kind of thing and I think if they had asked for an extra $10 for any kind of coverage, I would have objected simply because I would not have foreseen what could have happened down the line.

Senator HEINZ. I think that's probably a very accurate statement.

I remember the first time I went into an employer in Pittsburgh and found out what my take-home was actually going to be compared to the great salary I had been offered. I wondered, what happened to the salary? I think we all probably felt that way at one time or another.

One last question, and this is one we're going to get asked and it's one, whether we admit or not, we think of, too, and it's the toughest single question.

If we establish a program that provides the level and quality of care needed, and it's flexible so that as you need different levels of care, you can get it; it's humane to allow the best possible job of planning; it's delivered in a variety of settings so people could maximize their dignity quotient—the nagging question is whether or not the individual and families should have to have a substantial amount of financial responsibility for themself or their loved ones as well?

The reason I hestitate to mention this is that all of you have given your all; you've given everything you've got.

What happens if everybody isn't like you. What happens if somebody wants, let's say, to maximize as much of the family savings as they can to pass along to their kids?

There's nothing wrong with that and, yet, it raises a profound and terribly difficult question of public policy which people often refer to as kind of asset preservation, and for whose benefit?

For the average family, it doesn't seem to be much of an issue because nobody thinks of themselves as too well off and, yet, it's a very big change from our present system, as you know, which says before you get any help at all, you've got to be dirt poor. At the same time, people say you shouldn't have an asset preservation program where families can keep everything they have because that puts an unnecessarily high burden on everybody else.

Does anybody want to take a crack of this really nasty, mean, awful issue because that's what it is? It's probably just about as bad as the issue of abortion as a public policy matter.

Does anybody want to try to take that tiger by the tail?

Terry Idelson. I think that there should at least be a policy established that would at the minimum prevent families from going into bankruptcy because that is what happens.

Senator Heinz. Here is Ms. Singer who had to divorce her husband to keep body and soul together.

That shouldn't have to be the case. We can write an antidivorce law, but that isn't what you or I have in mind.

Terry Idelson. In our circumstances, that wouldn't help at all. It would not help.

Senator Heinz. No, not at all.

Terry Idelson. We're a family just starting out. We haven't really had time to really build a savings and we're wiped out from the beginning and there's nothing we can do about it.

Stephanie's medical bills are at the extreme and even to try to pay the 20 percent that is not covered would wipe out my husband's income in the first few months and there's nothing we can do about it. So, you just have to accept it and go on.

Senator Heinz. All right.

Jim, do you have another comment?

Commissioner Balog. What was very interesting, I thought, was Ms. Burnett's analysis of the unwillingness of people to chip in when they're working because you don't anticipate anything like this happening; so, people aren't willing to have anything taken out of their paycheck.

Senator Heinz has pointed out it's a $60 billion tab. It would mean something like $50 plus per month per working person to pay for that long-term care program. That's what it would work out to be.

You can do the numbers. There are 160 million employed people in America. So, you can figure out what the cost would be.

Most people, when they're asked what they would be willing to chip in, the answers come back, $5 or $10 a month. We're off by a factor of 10 or 20 in this thing. So, somewhere in here, we have got to come up with an efficient program and then spread that tax burden over a lot of people, all 160 million people.

I think that's what we're facing, what we started out with, and that's what I think we've got to come to grips with, but I think this has been most helpful.

We're looking at it from a spectrum of a 2-year-old to a 76-year-old lady and that's the kind of a problem we're going to deal with, complex, but it's a pervasive problem in our society and we've got to tackle it. Everybody has got to share the burden.

Thank you very much.

Senator Heinz. May I thank you, Jack, and ladies for being with us. We are extremely appreciative of the trouble you've gone to, the courage that you've shown in coming here and telling us about very real, very difficult, but very human and important stories of what life has been like for you and your loved ones and your family.

Thank you all very, very much. We're deeply in debt.

[At this point, there was a brief recess taken, at the conclusion of which the hearing continued as follows:]

Senator HEINZ. Before we start, I want to recognize some people who are here and, in particular, probably one of the most familiar faces before the Senate Committee on Aging, namely Maggie Kuhn, the National Convener of the Gray Panthers. Maggie, we are delighted, as always, to have you here and I'm glad you're going to give your testimony as well.

May I say we have, some additional testimony that has been submitted for the record. It will be a part of the record.

I have been admonished, is the best word, by some people who following George Washington's example, crossed the Delaware from New Jersey in order to be here.

Would all you New Jersey people raise your hands?

It's a packed house.

We're glad to have you here and we wish you would move permanently.

We have a very distinguished panel of advocates providers. We are most privileged to have the Secretary of the Pennsylvania Department of Aging, Linda Rhodes, here and I'm going to ask Linda to please start this panel.

Linda, welcome; thank you for joining us.

LINDA RHODES. Thank you.

Senator HEINZ. I might add Linda has testified on one previous occasion before our committee and, as usual, did a fine job.

STATEMENT OF LINDA RHODES, SECRETARY, PENNSYLVANIA DEPARTMENT OF AGING, HARRISBURG, PA

LINDA RHODES. Thank you very much, Senator Heinz. I'm really honored to be here this morning to testify before the Pepper Commission.

I have prepared written testimony and what I would like to do for my opening remarks is just to talk for a few moments on what I think some of the major issues are.

As a Commission, you're searching for some of the same answers to the very same questions that we're facing here in Pennsylvania.

Before I mention some of those questions and what we're trying to do, at the State, I think it's good to first look at, "what do we currently know?"

We certainly know that Pennsylvania is a major graying State. In fact, we're more so than most.

We also know that the 85-plus group is growing very quickly in Pennsylvania and that they need health care. We have seen this grow; there's been a 60-percent increase just during the last 10 years.

We also know, and it's the more dramatic fact that we know, that the demand for services is going to exceed supply.

We have a lottery in Pennsylvania which we're very grateful for and we have spent $4 billion for older people since we have had the lottery. However, next year, for first time in the lottery's history, we are going to face a deficit. There is no getting around that.

We also know that right now in Pennsylvania out of the Department of Aging, we're spending $4 million a week on pills. It's one-half of our budget and I think all of us would agree that that's not the best way of spending our money, on medications alone. It's feeding our deficit.

We also know in Pennsylvania that only about 16 percent of our budget now is from the Federal Government. Most of it is all State based. What that means is that the tables have turned—while we need to listen and work with the Federal Government, many of our responses and solutions have to be a State-solved one.

We, too, like you, are very frustrated with our own waiting list for services and some of the tough choices that all of us are going to have to face in deciding who gets what.

We've been asking ourselves some of these soul-searching questions through two different mediums.

One has been through a Intragovernmental Council on Long-Term Care and the other has been through discussions within our own administration of the Department of Aging. The Intragovernmental Council on Long-Term Care was established by an executive order from Governor Casey in 1988. The legislature liked it enough that they actually passed that as a part of law, through Act 185. The key policy questions before the Council are these:

Just what is long-term care? What services should be in the continuum of care and what services are missing?

We need to develop ways of looking at long-term care that's agency based, that all the agencies in State Government understand.

We're also asking ourselves, who should the long-term care continuum serve? Should it be just older people? Should the long-term care needs of the disabled be part of that continuum as well? We're asking ourselves, who needs it and will they get it?

A major question is how are they going to have access to that care?

We're also asking ourselves, does it make sense how we're organized right now in State Government to deliver this care? I would venture to say that many providers think we aren't well managed.

The other major question, of course, is how are we going to pay for all of this, once we even answer those sets of questions.

My written testimony outlines a number of strategies and programs and services that we offer at the State, but what I would like to do is dispense with that testimony and get to the bottom line. Here are the things that I think are the bottom line.

One is that the State and Federal Governments must become public policy partners. We aren't right now.

What occurs so much, and I think what we've learned from the whole experience with the Nursing Home Reform Act, is because we aren't partners in the whole planning process, because we view each other sometimes in a kind of paranoid fashion, many of the problems that the people here before us have all cited stem from the fact that we don't see ourselves as public policy partners to fix some of these problems. It also means the tables, as I have said, have turned.

We need to work with the Federal Government, but they need to work with us.

We have been solving some of these problems, dealing with some of the issues. We've really been on the front lines and in Pennsylvania, where most of our money is State-funded—(84 percent of that budget is State funded), it means we have to work through those solutions ourselves.

Our other bottom line is that the long-term care system must include more than just older people. It is not a geriatric system alone. We need to develop a long-term care system that meets the needs of all people, no matter what ages they are, that they are going to face over the long term, and it will force different networks to work together which is desperately needed.

I think it's a real hardship and it doesn't make any sense that someone who is mentally retarded, once they become old, the mental retardation system says, "Look, I don't understand aging services; you now have to become part of the Department of Aging," but we'll sit and say, "We don't understand the needs of someone who's retarded; you need to stay back in that system" and that individual stands there in between these two major systems.

Another bottom line is that the days of, what I call, parallel bureaucracies should be over. They should be out like the dinosaurs.

Our current way of structuring things is that we have these major departments, whether they are at the Federal level or at the State level and they don't work with each other. We keep tacking on, as you said, the patches and as a result, we never do develop a quilt at all, and it's a very tough thing to do because these agencies are so large.

If we achieve that kind of integration at the State level, then the problems that someone mentioned here before about attendant care, someone who's in their 50's who doesn't want to live in a nursing home, could be resolved. We need to be talking and working with the Department of Welfare so that individual is taken care of.

It also means, as Ms. Singer was mentioning about needing some long-term care services for someone who is brain injured, that we should work with and use the mental retardation network, and yet we tell the patient, "That's not the primary diagnosis."

Not unless we at the State level have these departments integrated are we going to be able to fix the problems that were raised here this morning.

The other bottom line is that in-home services are vital to individuals and their families and that's where much of our emphasis, the new trend in State funding, has gone. We need to support these families in many different respects and, basically, I think in-home services is the commonsense side of long-term care. It's what most of the people need most of the time. It's not all the fancy diagnostic kind of care that will cure people that we talked about before.

We're also going to need to manage care for people. It's very complicated to go through the whole maze of services that we offer, whether it be from the State Government or from Federal Government or from whomever.

Right now, we're going to need to know what's appropriate for that individual, especially if the State is paying for that ticket.

Currently, the State of Pennsylvania is paying $700 million a year for nursing home care and we spend less than $200 million for in-home services that everyone here has been talking about.

However, we need to manage it and it means from the State's view, we're going to be in a position to assess those needs of the individual and then manage the care for them.

Finally, the other bottom line is that we need to share financial responsibility. I think it's a myth when people think that as a result of the fall-out from the Medicare Catastrophic Bill, that older people don't want to pay. That simply isn't true.

What they want to do is pay for something that they need, something that they can afford to pay.

Right now, for the first time in our State, we're holding what we're calling Nexus hearings. I'm having hearings in five other cities and we've been asking older people, "What do you think about sharing in some of the costs?"

What they are telling us is that it is important to share some of the costs, but they want to know what it's for. They also want to make sure it's affordable and that we, as a department, or those of us who are providing the services don't lost sight of our mission so that if we are going to have some people pay for some of the care, which many of them have been willing to do, that we don't go off and become so concerned about raising money that we forget the mission of taking care of the poor from whence we all came.

The other thing that we've learned is a result of Pennsylvania's Family Caregiving Program. We've gone in with families as they have taken care of someone and we have discovered, which I think many of the legislature would be surprised at, is that people haven't used up all the funds we were willing to offer them. They've been very resourceful as family members.

However, what they need is some of these services and what we need is help in sharing in some of the costs. Perhaps, they can't afford $25 a day for adult day care; they might be able to pitch in for $5 or $10 and they need the State to pick up the rest.

I think that as many of us have said, we don't want you to become sidetracked or even disheartened over the experience with the Medicare Catastrophic Bill. I think we can all learn from it and go about the business of developing a serious and comprehensive long-term care program.

Long-term care is certainly, as we view it, the family issue of the 1990's. I think each one of us in this room can speak through personal experiences of caring for some family member, and it doesn't matter in terms of their age, but there has been some frail member within that family that needs long-term care.

I think when you had asked the question earlier about families and how much responsibility they should share, I think the problem is, if I could borrow the title from the book, from Families U.S.A., "We're all in this together."

I think the problem has been that we've asked these families, the ones that have testified before you today, almost to do too much. We've asked them or we have forced them to become martyrs and that's not fair. What it does mean is that we haven't viewed it as something where "we're all in this together."

[The prepared statement of Linda Rhodes follows:]

Statement by Linda M. Rhodes
Secretary, Pennsylvania Department of Aging
November 13, 1989

Good morning. My name is Linda M. Rhodes and I am Secretary of Aging for the Commonwealth of Pennsylvania. I am here today to speak on the issue of long term care and Pennsylvania's response to the expanding long term care needs of our growing population of older people.

In Pennsylvania we have particular cause for concern for two reasons. First, we are a major greying state with over 2.4 million people over age 60. At present, we rank second to Florida in the proportion of our older population to the rest of the population. And we rank fourth in terms of pure numbers of older people. Most significantly is that our over-85 population--the heaviest users of long term care services--has increased by more than 60 percent in this decade.

Our second reason for concern has to do with the way in which we fund long term care services in Pennsylvania. With the birth of the Pennsylvania Lottery in 1972, the decision was made to fund aging services through lottery proceeds. To our knowledge, Pennsylvania is the only state that devotes net Lottery profits to services for older people.

The good news is that over the years the lottery has funded more than $4 billion in services for older people. The bad news is that the cost of these services will exceed available lottery fund dollars for the first time in the Lottery's history in the 1990-91 fiscal year.

Coupled with this is the fact that the federal share of aging services resources has declined steadily since 1985, placing an even greater burden on our state's resources.

Although we remain optimistic that current aging programs will continue to be funded, our concern is that the shortfall will prevent new programs from being initiated and new persons from being served. As a preventive measure, Governor Casey has begun to put back some aging programs into the General Fund to free up more Lottery Fund dollars. But the need is great and it's growing.

Allow me now to address some of the ways in which we are beginning to address those needs in Pennsylvania.

<u>Preadmission Assessment</u> - Many of you have become familiar with the term preadmission assessment through the recent OBRA legislation. OBRA now requires all states to assess individuals applying for nursing home care for mental health, mental retardation or related disorders with the goal of assuring appropriate treatment of these individuals. In Pennsylvania, we've been assessing people before they enter the nursing home for the past four years.

The goal of our pre-admission assessment program has been to arrange for the most appropriate level of care for Medicaid-eligible nursing home applicants. What this means for the older person is that we have the ability in many areas of the state to offer intensive in-home services as an alternative to nursing home care. These services cannot cost more than 45 percent of the cost of the nursing home care. We have found that, on the average, where nursing home care cost $60 per day, we can provide in-home services to that person for about $23 per day.

In the 1987-88 fiscal year, we assessed 13,000 people. Of those, 23 percent had been referred to a higher level of care than was actually needed. Because of the community-based services we were able to provide, 14 percent were able to stay in their own homes or with family. For this, the Commonwealth spent a total of $10 million service dollars, as opposed to the $63 million in state and federal dollars that would have been spent on nursing home care.

Managed Care - The key to the Intensive In-Home Services program is managed care. Managed care means that we help the older person or family identify and tap the community-based services they need to maintain a quality of life within the home. Perhaps they need an adult day care center or respite care, homemaker services or personal care assistance. Most families don't even know what services are out there or which ones they are eligible for. With managed care, we are able put together the pieces of the puzzle for that family and help them tap the resources to pay for many of these services.

Family Caregiver Support Program - The Family Caregiver Support Program is one we're very proud of. Begun early in the Casey administration, this program places the emphasis on the families who are providing support to older relatives in the home.

A national survey on caregiving conducted by the American Association of Retired Persons showed that four out of five older people with physical or mental impairments are able to avoid institutionalization because of assistance provided by family members or friends. It is estimated that there may be as many as 7 million caregiving households in the United States providing an average of 12 hours of care each week.

The Family Caregiver Support Program offers financial help, benefits advice and some hard services to ease the stress associated with caregiving. In some cases, we've been able to add wheelchair ramps, stair climbs and other home modifications to help make the older person more independent of the caregiver.

The Family Caregiver Support program is currently a demonstration project in thirteen counties.

Transitional Care - The Transitional Care program is another demonstration project started under the Casey Administration. Transitional Care focuses on older people who are being discharged from an acute care setting to the home. What we do is work with hospital discharge planners to identify those older people who will need intensive in-home services immediately following their hospital stay and provide those services on a short-term basis. The goal of the transitional care program is to aid the person's convalescence to prevent re-hospitalization or premature nursing home admission.

Most of the older people who have benefited from transitional care are those who live alone or whose spouses or families are unable to provide the care they need. An initial evaluation of the program has demonstrated that the program has been successful in providing the needed services to reduce the functional dependency of the patient on the caregiver and in preventing re-hospitalization or premature institutionalization.

Cost-sharing - In addition to the direct benefits provided by both the Family Caregiver and Transitional Care programs, another significant factor is that we have introduced cost-sharing into these programs.

Cost-sharing is a new concept in aging programs and heretofore untried because of prohibitions in the Older Americans Act. Currently, older people with poverty level incomes are given priority for services. But often, as I travel across the state, I hear from older people and their families that, while they cannot afford to pay the full cost of the service, they would be willing to pay a share of that cost. Maybe they can't afford $15 a day for adult day care, but they could pay $10.

I firmly believe that cost-sharing is the wave of the future and a legitimate way to expand services to more people without draining service dollars. Pennsylvania is being observed by other states as well as the Administration on Aging to see if cost-sharing is indeed a viable option for aging services.

Long Term Care Council - The Commonwealth of Pennsylvania is spending nearly $1 billion dollars annually for various aging services. These services are offered through a number of state agencies without any coordination or strategic planning. The result is a fragmented service delivery system with overlaps and gaps.

In an effort to improve this system as well as to assure that adequate and appropriate long term care services are accessible and available to those in need of them, Governor Casey in 1988 established the Commonwealth's first Intra-Governmental Council on Long Term Care. The Council is now the vehicle through which planning and policy development for long term care is conducted. I am privileged to chair this council and to have on it other members of the Governor's Cabinet, several legislators, representatives of the long term care industry, the business and labor communities and consumers.

Over the past months, the Council and its committees have been working diligently for long term care reform in the Commonwealth. We began by looking at the current system--who was doing what and did it make sense or was there a better way.

The Council is now preparing a comprehensive report that responds to some of these questions.

What is needed? A long term care continuum that comprises a balance of settings, from in-home, to community- and facility-based care.

Who needs it? Initially, the 18 and over functionally disabled population.

How will it be delivered locally? Through a central point of entry and maintained through a care management system.

How will we pay for it? By creating complementary roles for the public and private sectors.

How will we manage it? Through reshaping the state's organizational responsibilities to achieve better coordination.

I sincerely believe and hope that you would agree that Pennsylvania is doing its part in attempting to respond to the complex issue of long term care. But it's a balancing act at best and smoke and mirrors at worst. We are reaching our limit in terms of what we can do with the precious little resources we have left.

If there's one plea I make to you this morning, it is that the federal government work in partnership with states to develop a national long term care policy, one that addresses the needs--not just of the frail older population--but of all generations.

In earlier testimony on this issue, I cited three myths of long term care: the myth that long term care is just nursing home care; that Medicare pays for long term care; and that it only affects a handful of people. Let me add to them a fourth myth: that long term care only applies to older people.

Permit me to invoke the title of a book published by Families USA entitled, "We're All In This Together." As the title implies, long term care is not just an older people's problem--it's everyone's problem. Moreover, it's everyone's responsibility.

As you well know, one of the biggest problems with the Medicare Catastrophic legislation was that it wasn't a shared responsibility. Older people felt unfairly singled out to shoulder a burden for a problem they didn't create.

Shared responsibility is what our social programs have been built upon throughout history, and what have made them acceptable and successful.

It's time to reprogram our thinking in long term care. Not to say, "this is for children and this is for older people," but instead to say, "this is for the frail among us, regardless of age or income."

There are those who would have us choose between the generations--who gets the medical care, who gets social programs. They would have us choose between the child born with spina bifida or the 80-year-old who needs dialysis.

As policymakers, we must refuse to make those choices. We must recognize that there is no trade off between young and old, because in a trade off nobody wins. We have to get rid of the "mine, yours and theirs" mindset and build a long term care system built on the time-proven philosophy of sharing the burden.

To those who advocate for children, I ask you to look ahead to what happens to those children with long term care needs who become young adults and middle-aged. We need a system that plans ahead for the long term care needs of our children.

To those in the aging network and advocates for older people, I ask you broaden your thinking as well. The strength of the aging network has been well demonstrated. Now it's time to channel that energy into a unified front, one that advocates for the long term care needs of people across generations.

Because what we are really talking about is families. The strength of the family unit is that its members look out for the best interests of one another. And that's the kind of thinking we need to promote in developing a national long term care policy.

To policymakers, I ask that you recognize long term care as the social issue of the 90's and that you work in partnership with states to develop a long term care policy that leaves no one out, no one behind; that recognizes and rewards the contributions of families in caring for its own members; that acknowledges the home as the preferred place of care and that focuses resources on services in the home; that shields families from the crushing costs of long term care.

Indeed, we are all in this together.

Thank you.

Senator HEINZ. Linda, very well said and very good suggestions which we'll come back to in a moment.

Now, I would like to call upon someone who never looks at all gray, but nonetheless claims to be a panther of that type, but is always ready to spring, Maggie Kuhn.

STATEMENT OF MAGGIE KUHN, FOUNDER AND NATIONAL CONVENER, GRAY PANTHERS, PHILADELPHIA, PA

MAGGIE KUHN. Thank you, Senator Heinz. It's a delight to be here.

I am Maggie Kuhn, Founder and National Convener of the Gray Panthers. Members of our board of directors are here with me and we all warmly commend you for your efforts to deal with the crisis of long-term care in the context of the whole health-care crisis.

We are an intergenerational group, age and youth in action. We are presently 40,000 members strong, and working in 80 local chapters or networks across the country.

For more than two decades we have been concerned about health care, even before we organized; and in the present situation, health is a national priority.

We are going to be celebrating our 20th anniversary in Washington, DC in May 1990 and extend a warm invitation to you to join us in our celebration.

We are also holding a national convention at that time to affirm again the top priority, which is health care.

Now, the health care that we seek is publicly supported out of general revenues. It is controlled by the community in which those revenues are spent and it is free to every woman, man and child in America.

We believe that the time is at hand, the historical moment has arrived, when Americans across the country will support this idea. It's not a dream for the 21st century. It is now.

Last year, the Gray Panthers conducted 20 health hearings in different parts of the country and have gathered an enormous body of testimony from hundreds of witnesses who testified as to the failure of our present system and built the case for our new system.

In our national convention in 1988, we appointed a special commission on health care to review and analyze the testimony of those hundreds of witnesses. The commission is at work and is being assisted in its work by a board interdisciplinary group of knowledgeable people in health care. We want the work of the commission to be accurate, timely, and thoroughly responsible.

In 1985, a Gray Panther delegation visited Canada at the invitation of government officials in health care.

We were invited to examine and probe Provincial and Federal systems.

We learned that they had done it in various stages. Province by Province. They also had set up initially a comprehensive hospital care system. They also set up another nursing home care system. They laterally developed a preventive service system.

We were impressed with the accessibility and the varieties of health services provided out of provincial and general revenues.

Our plan is to launch at our convention and our celebration of our 20 years of advocacy another initiative for health care. We'll be working with nurses, physicians, therapists, administrators, and health planners in the system and we are convinced that we will be heard.

Health care in America depends largely on one's income. In the last 10 years there has been a widening gap between the rich and the poor.

Millions live in impoverished ghettos where infant mortality is higher than in the Third World, where there is chronic hunger, and homelessness.

Now, how can there be personal health when that society is sick?

So, the system that we must devise has to take into account our present state of economy and social development and I think the comprehensive plans that are envisioned in our plan will certainly help to move us along.

We are learning from the health-care system that we observed in Canada. We have also studied in depth the physicians' system that has been proposed in the New England Journal of Medicine. That has been a very comprehensive plan, but we think of a delivery system as involving a team. The physicians are not on top and it isn't hierarchy, but it is a team of nurses, therapists, health planners, and physicians, and we're devising a stretcher that reflects the team arrangement for administration and care.

We're also working with schools of medicine and nursing and so forth to enable the future health providers and health professionals to be aware of the new monumental needs that two revolutions have given, the demographic revolution and the technological revolution.

We have been shortchanged in our health-care system by these forces, and I'll very briefly summarize:

We have closed public hospitals. The nonprofit hospitals are disappearing because of the increasing takeovers by profitable chains of hospitals. We have closed emergency rooms. You could be bleeding; you could be near death, but you will be turned away from an emergency room if you do not have money or insurance.

This is in direct denial of the health care that we seek to provide.

Jack Zucker who is here, I credit him with his wonderful one-liner; "We have come to the time when the bottom line has replaced the Hippocratic Oath."

We are caught in a system that is not good for the health. Health in our view is a basic human right, not a privilege. Let's not forget the definition of "health" of The World Health Organization of The United Nations: Health is the state of complete physical, mental, and social well-being, and not merely the absence of disease and infirmity.

[The prepared statement of Maggie Kuhn follows:]

TESTIMONY BEFORE THE PEPPER COMMISSION: NOVEMBER 13, 1989

MR. CHAIRMAN AND MEMBERS OF THE PEPPER COMMISSION:

I AM MAGGIE KUHN, NATIONAL CONVENER OF THE GRAY PANTHERS. MEMBERS OF OUR NATIONAL BOARD ARE WITH ME IN THIS HEARING, AND WE COMMEND THE COMMISSION FOR YOUR CONCERN AND FOR YOUR EFFORTS TO ADDRESS OUR NATION'S "HEALTH CARE CRISIS."

WE ARE A NATIONAL, INTERGENERATIONAL ORGANIZATION WITH SOME 40,000 MEMBERS AND 80 LOCAL GROUPS IN DIFFERENT PARTS OF THE COUNTRY COMMITTED TO COMBAT AGE DISCRIMINATION AND ALL OTHER FORMS OF PREJUDICE; AND TO PROMOTE PEACE, ECONOMIC AND SOCIAL JUSTICE, AND UNIVERSAL HEALTH CARE. WE ARE "AGE AND YOUTH IN ACTION."

FOR NEARLY TWO DECADES HEALTH HAS BEEN A MAJOR GRAY PANTHER ISSUE. TWO NATIONAL TASK FORCES HAVE OBSERVED AND ANALYZED THE COMPLEX SOCIAL AND POLITICAL FORCES THAT HAVE CREATED OUR PRESENT COSTLY, FRAGMENTED, OVER-SPECIALIZED SYSTEM THAT HAS BEEN INACCESSIBLE TO OVER 37 MILLION AMERICANS WHO DO NOT HAVE HEALTH INSURANCE. THE "TAKE-OVER" OF NON-PROFIT HOSPITALS BY POWERFUL FOR-PROFIT HOSPITAL CHAINS AND THE CLOSING OF COMMUNITY HOSPITALS AND CLINICS HAS DEPRIVED SICK PEOPLE OF CARE IN EMERGENCY ROOMS. THE BOTTOM LINE HAS REPLACED THE HIPPOCRATIC OATH!

ACCORDING TO THE WORLD HEALTH ORGANIZATION, OUR STANDARDS OF LIVING LARGELY DETERMINE OUR STATE OF HEALTH. IN THE LAST 10 YEARS THE CHASM BETWEEN THE POOR AND THE RICH HAS WIDENED. MILLIONS ARE LIVING IN IMPOVERISHED GHETTOS CURSED WITH DRUG RELATED CRIME, ESCALATING INFANT MORTALITY, HOMELESSNESS AND CHRONIC HUNGER. WE ARE A SICK SOCIETY.

THE UNITED STATES HAS FOCUSED ON ACUTE CARE, BUT GROSSLY NEGLECTED LONG-TERM CARE, PREVENTIVE CARE AND EDUCATION FOR WELLNESS. THE GRAY PANTHERS WELCOMES AND STRONGLY SUPPORTS THE LEGISLATION OFFERED BY REPRESENTATIVE RONALD DELLUMS.

IN APRIL OF 1985, AT THE INVITATION OF CANADIAN HEALTH OFFICIALS, GRAY PANTHERS WENT TO MONTREAL AND QUEBEC TO STUDY THE CANADIAN HEALTH SYSTEM. WE LEARNED THAT IT WAS CREATED IN STAGES, AND PROVINCE BY PROVINCE. FEDERAL AND PROVINCIAL ACTION FIRST ESTABLISHED A UNIVERSAL HOSPITAL ENTITLEMENT PROGRAM, THEN A UNIVERSAL MEDICAL PROGRAM FOLLOWED BY NURSING HOME CARE AND PREVENTIVE SERVICES.

LAST YEAR GRAY PANTHERS CONDUCTED 20 PUBLIC HEARINGS IN DIFFERENT PARTS OF THE COUNTRY. ONE HEARING WAS HELD IN REPRESENTATIVE WILLIAM GRAY'S BRIGHT HOPE BAPTIST CHURCH IN NORTH PHILADELPHIA. HUNDREDS OF WITNESSES PRESENTED IRREFUTABLE EVIDENCE THAT OUR PRESENT SYSTEM IS FAILING.

AT OUR NATIONAL CONVENTION IN CHICAGO IN NOVEMBER 1988 WE SET UP A COMMISSION FOR A NATIONAL HEALTH PROGRAM, CHAIRED BY DAVID DANIELSON, HEALTH PLANNER FROM CAMBRIDGE, MASSACHUSETTS. THE COMMISSION HAS BROUGHT TOGETHER A DISTINGUISHED, INTERDISCIPLINARY GROUP OF HEALTH PROFESSIONALS - NURSES, PHYSICIANS, THERAPISTS, EDUCATORS AND PUBLIC HEALTH OFFICIALS - AND UNION LEADERS. THE MEMBERSHIP OF THIS COMMISSION PROVIDES ASSURANCE THAT ITS WORK WILL BE THOROUGH, ACCURATE AND INNOVATIVE. THE PLAN WHICH THE COMMISSION WILL RECOMMEND WILL BE COMPREHENSIVE: IT WILL BE PUBLICLY SUPPORTED AND COMMUNITY CONTROLLED; AND IT WILL BE FREE TO ALL AMERICANS.

THE PLAN WE ENVISION WILL BE CARRIED OUT BY TEAMS OF HEALTH CARE PROVIDERS - AN ESSENTIAL CHANGE FROM THE PRESENT PHYSICIAN-DOMINATED SYSTEM.

THE GRAY PANTHER TOP PRIORITY FOR 1990 WILL BE THE ESTABLISHMENT OF A NATIONAL HEALTH PLAN. THE HEALTH COMMISSION IS DEVELOPING A CONCERTED ACTION STRATEGY TO BE ADOPTED BY OUR NATIONAL CONVENTION IN MAY OF 1990, AND CARRIED FORWARD IN OUR 80 LOCAL NETWORKS. DURING THE GRAY PANTHER CONVENTION IN WASHINGTON DELEGATES WILL RALLY ON THE CAPITOL STEPS AND THEN VISIT THEIR SENATORS AND CONGRESSMEN. AFTER THE CONVENTION SPECIAL EFFORTS WILL BE MADE TO MEET WITH STUDENTS OF NURSING, MEDICINE, THERAPY AND SOCIAL WORK TO DEEPEN THEIR PUBLIC AWARENESS AND SECURE THEIR SUPPORT.

HEALTH CARE IS A BASIC HUMAN RIGHT - NOT A PRIVILEGE!

Senator HEINZ. Thank you very, very much.

Over the nearly 15 years that I've known you, you haven't lost a step.

I'm going to have to go out of order a little bit because I'm informed that Charles Daly, who is the Vice President of the Delaware Valley Hospital Council and Dr. Jacobson who is accompanying him, are going to have to leave at 12:30.

So, let me at this point call on Charles Daly and Dr. Jacobson for their testimonies.

STATEMENT OF CHARLES DALY, VICE PRESIDENT, DELAWARE VALLEY HOSPITAL COUNCIL, PHILADELPHIA, PA

CHARLES DALY. Thank you, Senator Heinz. Dr. Jacobson has to leave. I will be here for the full panel session.

I am Charles Daly, Vice President of the Delaware Valley Hospital Council, which includes 86 member hospitals in southeastern Pennsylvania.

Today, I would like to focus on the problem of access to emergency room services and care.

This problem brings into sharper focus the serious afflictions of our health-care system.

The Hospital Council is grateful to you, Senator, and to the Commission for taking the time and care to examine the growing difficulties faced by many people in this area with obtaining access to the health care they require.

In Philadelphia, the demand for emergency services has grown dramatically during the last several years with a growth in use rates approximating 9 percent annually. This has resulted in longer waits for services, particularly in innercity hospitals, and occasionally for delays in admission of patients who have severe conditions.

Most of the patients who present themselves at emergency rooms are walk-in patients; however, the symptoms of stress in our city are apparent when emergency departments request that patients transported by city ambulances be diverted elsewhere. This typically occurs in the winter months; for example, last January, there were occasions in which at least 12 of Philadelphia's 34 emergency rooms requested diversion status between noon and midnight. We anticipate that these diversion requests, and please do note I do not say closure because hospital emergency rooms do not close, they accept whoever appears at their door for treatment, we anticipate that these diversion requests will again increase during the upcoming winter months.

Decreased access to emergency rooms is a problem that affects us all. The person for whom diversion is sought may as well be a bank president as a crack dealer. Clearly, we must understand the causes of emergency room overcrowding in order to seek out long- and short-term solutions.

Why are hospitals finding it increasingly difficult to respond when emergency care is required?

First, let us consider the types of patients who rely upon hospital emergency rooms for care.

In innercity areas, there are increasingly high proportions of persons who are drug users or abusers who present themselves for care. Some emergency departments estimate this to be 50 percent or more of the patients that they see. Of the most severe trauma cases that we have, many, if not most of them, are directly attributable to drug abuse. In Philadelphia alone, the number of cocaine-related emergency room admissions reported to the Federal Drug Abuse Warning Network increased 10 times between the second half of 1985 and the first half of 1988. Tragically, the proportions of babies born with cocaine or other drugs in their system at time of birth is increasing at large rates. Many newborns have nowhere to go. On any given day in Philadelphia, there are 40 babies waiting in hospitals for mothers who will never return for them.

The severely mentally ill also arrive at overcrowded emergency rooms to seek care. During the last year, the number of persons for whom involuntary commitment was sought increased 42 percent in Philadelphia, increasing from 4,800 to 6,800 persons. The publicly funded mental health system is in disarray. In too many instances, there's too heavy a reliance upon a few overcrowded hospitals to provide emergency services when a crisis emerges. The severe shortage of community based chronic institutional services to meet the community needs offers little hope for improvement.

Increasing numbers of people with AIDS and homeless also go to hospitals where there is nowhere else to turn.

Let me now address another aspect of the problem of access to hospital and emergency room care, focusing on the economically disadvantaged. This includes, children, adults, and the elderly. The problem, Senator Heinz, as you mentioned at the beginning of today's session, that we have is a very great problem of lack of access to care for the medically indigent. In Pennsylvania, nearly 9 percent of the population lacks health insurance and in Philadelphia, approximately, the same percentage of the population or nearly 140,000 people lack any health insurance whatsoever. The medically indigent are only half as likely to have access to a regular source of care as the insured. Lacking access to primary care, the medically indigent use Philadelphia hospital emergency rooms at rates four times those with private insurance and twice those with Medicaid. Oftentimes, persons present themselves at emergency rooms with conditions that are much more severe than they would be if they had earlier access to care. Oftentimes children, as you pointed out earlier, also present themselves for minor or less urgent illnesses when they should be receiving more basic primary or preventive care in another setting.

In Pennsylvania, we've been grappling unsuccessfully for more than the last year-and-a-half at the State level with the problem of providing health insurance to the medically indigent. We've learned that the profile of the medically indigent includes the socioeconomically disadvantaged with more than half being poor minorities. We know that sizable numbers of the uninsured are young adults or children who reside in households where the main wage-earner is employed; approximately two-thirds of the medically indigent reside in these households. The problem with the medically indigent is a problem of the poor. We know that nearly half of those with incomes below 150 percent of poverty are not covered by the State Medicaid Program. Expansion of Medicaid eligibility, I would suggest, is an important part of a solution to the problem.

Policy leadership is needed to help States break the logjam of providing health insurance to the medically indigent who are employed, and to provide increased Federal funding for expansion of Medicaid benefits to the poor.

Access problems, of course, are not restricted to the medically indigent. We have a problem in this city that the elderly and others face with a very severe shortage of nursing home beds. We, at the Delaware Valley Hospital Council, have documented days where more than 200 patients remain in hospital beds who should not be there because their conditions do not require the acute care that hospitals have to offer. These are subacute patients who do not have access to nursing home care because there is no bed available for them.

Annually, our hospitals provide over 37,500 subacute days of care to people without access to care in more appropriate settings.

We have worked at the State level to try and help resolve this problem, at least on a temporary basis, by using acute care hospital bed units for long-term care. We've run into many obstacles in this regard, including costly plant and program conversion requirements, a moratorium on capital costs for nursing home development and very low reimbursement rates.

We need leadership at the national and the State level in order that we can forge out solutions to relieve the access problem for long-term care.

Hospitals, as providers of last resort, cannot afford to shoulder the heavy financial burden of care for the medically indigent or for those who require chronic and rehabilitative care in other settings.

Hospitals should not be expected to be taxing agents by shifting responsibility for under-reimbursed Federal and State programs to a diminishing pool of persons with private insurance coverage.

In southeastern Pennsylvania, our hospitals provided in 1988 free care and bad debts amounting to more than $136 million. The number of acute care hospitals sustaining operating losses increased from 18 in 1987 to 32 in 1988, or more than half of those reporting. Four hospitals, all serving large numbers of the poor, the medically indigent, and Medicare and Medicaid beneficiaries, currently are in bankruptcy proceedings.

The economic problems we face are, in part, the result of the same public policy shortcomings which have come forth today. These shortcomings have impeded access of the disadvantaged, the young and the old, and the severely mentally ill to the medical care that they require.

We urge your leadership in pursuing solutions to the major challenges which confront the health care delivery system.

Thank you for your attention and I am here to answer your questions as is Dr. Sheldon Jacobson, who I might introduce, on my left. He is Director of Emergency Medical Services at the Hospital of the University of Pennsylvania.

Senator HEINZ. With the permission of the other witnesses, I would like to address one or two questions to Dr. Jacobson, because he's on the firing line. He's right there where the shells land in the trenches.

Dr. Jacobson, since you do see and treat so many patients everyday as a primary care provider, as opposed to an emergency care provider, I was wondering if you could describe how many of those individuals are, in effect, members of uninsured families with children? Is it a small fraction, a large fraction; what is it?

STATEMENT OF DR. SHELDON JACOBSON, DIRECTOR OF EMERGENCY MEDICAL SERVICES, HOSPITAL OF THE UNIVERSITY OF PENNSYLVANIA

Dr. SHELDON JACOBSON. Senator, we have reviewed our statistics——

Senator HEINZ. You're at the University of Pennsylvania?

Dr. SHELDON JACOBSON. I'm at the University of Pennsylvania.

We've reviewed our statistics recently and our program sees approximately 100,000 visits a year and of the patients that we admit, about 92 percent have some form of health insurance that covers all or nearly all of their health care.

On the other hand, of the patients who do not get admitted, two-thirds of the patients we serve do not have health insurance.

Another way of looking at it is that of the patients we see in our emergency department, only 25 percent have emergent or urgent problems and the rest are really using us for intercurrent minor illness or primary care in lieu of a primary care physician. A lot of the care that we give is given without the hope of continuity of care in that the patients are sent out without the assurance that they're going to be picked up by a primary care provider and the appropriate continuity is going to be maintained.

I hope that answers your question.

Senator HEINZ. Do I understand that 75 percent, therefore, of the care you deliver in emergency rooms is nonemergency care?

Dr. SHELDON JACOBSON. Yes, approximately that.

Senator HEINZ. And that is to the entire population that is served?

Dr. SHELDON JACOBSON. That's correct.

Senator HEINZ. And that 75 percent are principally people who are uninsured?

Dr. SHELDON JACOBSON. That's correct.

Senator HEINZ. That's a staggering, staggering amount of nonemergency care delivered.

Why do people who provide emergency care keep doing it if they're not trained—well, I suppose you are trained to provide any kind of health care, but what price do we pay in addition to a financial one for that mismatch of resources?

Dr. SHELDON JACOBSON. Well, we pay a significant price.

First of all, our debt is exceedingly high in that operation, as you can well imagine, and what we are doing is essentially taking resources from the critically ill and injured patients and applying those resources to the less severely ill patients.

We simply can't erode the quality of our practice by closing the door to these patients. We cannot say, you know, that your illness is not worthy of our care or interest; so, the door is kept open.

We try to triage our efforts so that the sickest patients get the care first, but we guarantee anyone who wants care will get care within our institution and within the other institution that I'm familiar with in the Delaware Valley.

Senator HEINZ. What proportion of that 75 percent of all the people you see are children?

Dr. SHELDON JACOBSON. Well, at our institution, we do not see children because we are next door to Children's Hospital. So, I can't answer that question.

Senator HEINZ. So, you can't assess the health status of children?

Dr. SHELDON JACOBSON. I am sure, if anything, it's slightly worse because in speaking to my colleagues next door, their debt is running, if anything, a little higher than my own.

Senator HEINZ. Among the adults you see, are there people who by postponing seeking care because they don't have continuity of care, they don't have medical histories that anybody follows, have put themselves in either a life-threatening or debilitating situation or one that is almost certain to bring about hospitalization that would not otherwise have been necessary had they had a normal relationship to a primary provider?

Dr. SHELDON JACOBSON. Well, certainly, medical science has determined that there are a number of disease entities that can be prevented by case finding and preventative health care measures. Such entities as hypertension, breast cancer, and gastrointestinal cancer have been shown that once detected early have a very high cure rate.

Very few of our patients live with the benefit of preventative health care.

Because in the city of Philadelphia there are six medical schools and a large number of hospitals, I doubt that there are many patients who are allowed to linger while deteriorating without getting medical care; so, if they present themselves, I'm sure they will be absorbed into the health-care system. So, we do not see the kind of deterioration that you're alluding to. I cannot say it does occur.

What I do see as a major problem is the lack of preventative health care measures and planning so that those entities that could be prevented, if they were detected early, are not readily being taken care of in our population.

Senator HEINZ. What would some of those be?

Dr. SHELDON JACOBSON. Early detection and treatment of hypertension, breast cancer, gastrointestinal malignancy, prenatal, and "well baby" care.

Senator HEINZ. Thank you very much, Dr. Jacobson. I know you have to leave. The hour of 12:30 has arrived. Thank you very much for being with us.

I would now like to call on Mary Kay Pera, the Executive Director of the Pennsylvania Association of Home Health Care Agencies and more importantly, Coordinator of the Pennsylvania Long-Term Care Campaign.

STATEMENT OF MARY KAY PERA, EXECUTIVE DIRECTOR, PENNSYLVANIA ASSOCIATION OF HOME HEALTH CARE AGENCIES, AND COORDINATOR, PENNSYLVANIA LONG-TERM CAMPAIGN, HARRISBURG, PA

Mary Kay Pera. Senator Heinz, Mr. Balog, honored guests; good afternoon.

As you indicated, I am the Executive Director of the Pennsylvania Association of Home Health Care Agencies and I'm also co-coordinator of the Pennsylvania Long-Term Care Campaign.

On behalf of my association, the campaign, the families who need long-term care coverage now and those in the future and with an ever-present memory of my mother and father, thank you very much for holding this hearing. Thank you for your interest and I'm really very honored to participate.

Senator, with your permission, I'm going to abbreviate my comments, but I would appreciate it if you would enter my entire statement in the record.

Senator **Heinz.** Without objection, the entire text of your remarks will appear in the record.

Mary Kay Pera. Thank you, sir.

Senator, our Nation faces a number of very pressing issues right now that are competing for our attention. My comments are going to be specific to one such critical issue and that is the issue of long-term care.

To reiterate, the security of millions of American families is being threatened as they try to deal with this issue and increasingly, as you've heard today among our panelists, they don't know where to turn.

The Pennsylvania Long-Term Care Campaign believes that the answer lies in the enactment of a national comprehensive long-term care program. Such a program should cover home care and facility-based care, be financed as broadly as possible, much like Medicare and Social Security is, and should assist families, not replace them.

Now, as Secretary Rhodes said, Pennsylvania is struggling with this issue right now, but we believe it's bigger than what one State can handle. It's just too big for individual States and, therefore, we must seek a national solution.

The case for a national solution, I think, was borne out by the people we heard from in the first panel. I would just like to summarize for you why I think that they said that the time for long-term care has come.

First, advances in medical technology:

People are surviving traumatic accidents, traumatic illnesses, long illnesses, acute illnesses. While many of them who do survive recover fully, many do not and, as you have heard, require years of care.

Second, as you heard, we are an aging population and, of course, with advanced age, we are more likely to need assistance.

Third, as you heard, it's not just about the elderly; it's about children; it's about adults under 60. For the adult disabled person, home attendant care is the key to their independence and ability to participate in school work and recreation.

Fourth, there's the cost. Surely, we got the message on the cost today. Nursing home coverage right now is exorbitant.

Public and private coverage for hospitalization is usually always available, at least for the most part.

Home care, long-term care in particular, is very limited. As for the private long-term care insurance, it's currently covering about 1 percent of all long-term care and, quite frankly, that's because it's outside the realm of possibility for most Americans. Policies are restrictive; they've very expensive. Most families cannot afford them and where coverage does exist, there's usually a limitation. You heard what happened with Christina Rodgers.

In a recent study, Consumer Reports could find no best buys in the private insurance market.

Now, as for public programs, Medicare covers 2 percent of long-term nursing home care and as you, Senator, know very well, no long-term home care.

Medicaid is covering about 40 percent of all nursing home care, but as we've heard, people have to spend-down in order to use the program.

There are a number of public home-care programs available in Pennsylvania through the Departments of Aging and Welfare. Unfortunately, as Secretary Rhodes, herself said, the number who need the service exceeds the available resources.

As I said, private out-of-pocket is overwhelming. Nursing home coverage is running at about $35,700 a year these days. Most people cannot afford that and home care, which is usually provided on a part-time intermittent basis and supplements the care families provide, is costing between $45 and $60 a visit and anywhere from $25 to $200 a day, and what happens is the need presents itself a lot of times when families have responsibilities for small children or teenage children, children going into college; so, then parents are in a position where they have to make a choice; do I take care of my children or do I take care of my parents?

Here is another issue that has not really been raised today and that is that business is being affected. By the year 2000, the shrinking U.S. work force will be heavily dependent upon women and minorities, and women traditionally have been the caregivers as you, Mr. Balog, observed. Women can't be in the work force if they're going to be taking care of their families at home. Without help, you're trying to balance work and caregiving and you end up with absenteeism, personal illness, decreased productivity, and then it becomes a bottom-line issue and our ability to compete in what is now a global market at stake.

So, these are some of the key reasons why long-term care is a family issue. It's time has come. It's an issue that is begging for a solution.

Families are faced with mom or dad or a chronically ill child or an adult needing care and little help available.

I would like to just comment briefly on a couple of other issues:

Quality assurance.—It's been raised by our first panel. I implore you to make sure, whatever program we do develop, that quality assurance is an important part of it and I say so both from the home-care and from the facility-based care perspectives.

Furthermore, we are facing an acute shortage of qualified long-term care workers and I think Congress, Senator, should struggle to provide a climate that makes access to training possible and also makes fair wages possible so that we can get the home-care workers needed.

I would like to end my comments on a personal note if you wouldn't mind.

My own family has been affected by this issue. My father lost one leg and then a second leg to gangrene, secondary to diabetes. He learned, amazingly enough, to walk on two protheses and his key, I think, was my mother, my brothers, my sisters and I, who helped to take care of him. He just absolutely did not want to go to a nursing home and, fortunately, he did not have to. He remained at home and stayed on the first floor and one day, he just simply laid back in his bed which we had set up in the living room and died peacefully as he would have wanted it.

My mother was not quite so lucky. When her health began to fail, which was about 3 years after my father died, she had to be hospitalized and, sadly, she could not go back home because there wasn't anybody there. All of us had to work to meet our family responsibilities. So, because she could not get home care, she was not able to go home. She was discharged from the hospital to a nursing home and she deteriorated there and had to be rehospitalized, was discharged again to a nursing home, and died shortly thereafter.

Now, my parents would be horrified that I'm talking about them here in this public setting. They were proud. They worked all their lives. My father was a farmer; my mother was a domestic and a factory worker; she worked in a vegetable-processing plant. They struggled from paycheck to paycheck, but they did meet their obligations to their family and to their country. In the end, they could get institutional care, thanks to Medicare, but my mother, in particular, was discriminated against because of her need in that she wanted to go home, could have gone home, but this wasn't available to her. Purchasing long-term care coverage was out of the question for them and paying out-of-pocket, of course, was also out of the question. That was their story, one small story and, in turn, it's part of my story, part of the reason why I'm here today. I tell it only to reiterate that the system we have inplace is just not adequate, particularly for long-term care and I think we have to do better.

As a nation, we've always counted on our families to take care of one another and when they needed help, we would jump in. What we have said is that an increasing number of American families need the help of Government once again.

You raised it, Senator; you said that a concern is being expressed by some that it might be too expensive and in light of the budget deficit and the other priorities, in light of what happened with Catastrophic, maybe now isn't the time.

Well, my response is that Catastrophic did not cover long-term care. We know what we're asking for is going to be a major commitment, but we can't use Catastrophic and we can't use the budget deficit as a reason not to act.

It is an issue—long-term care is an issue that's not going to go away. We can't hide from it. It demands action now and I believe that we will find a way.

We are a resilient and resourceful nation and if you think of this century, there are countless examples of what we've been able to do when we put our minds to it.

We out here are prepared to do our part and we're counting on you, Senator Heinz, and I know we can, to help us, to help us figure this one out.

[The prepared statement of Mary Kay Pera follows:]

STATEMENT ON THE NEED FOR LONG TERM CARE

PRESENTED

TO A

JOINT SESSION

OF

THE PEPPER COMMISSION

AND THE

SENATE SPECIAL COMMITTEE ON AGING

NOVEMBER 13, 1989

MARY KAY PERA
EXECUTIVE DIRECTOR,
PENNSYLVANIA ASSOCIATION OF
HOME HEALTH AGENCIES

CO-COORDINATOR, PENNSYLVANIA
LONG TERM CARE CAMPAIGN

Senator Heinz. Other members of Congress. Honored guests. Good morning. My name is Mary Kay Pera. I am Executive Director the Pennsylvania Association of Home Health Agencies and Co-coordinator of the Pennsylvania Long Term Care Campaign. On behalf of my association, the Campaign, the families who need long term care now and in the future, and with an ever present memory of my mother and father, thank you for your interest and for holding this hearing. I am honored to participate.

Our nation faces a number of pressing issues that are competing for our attention. My comments are specific to one such critical issue: the growing demand by families for long term care. The security of millions of American families is being threatened as they try to deal with the demands of long term care, and increasingly they don't know where to turn. The Pennsylvania Long Term Care Campaign believes the answer lies in the enactment of a national, comprehensive long term care program. Such a program should cover home care and facility-based care, be available to everyone, regardless of age or income, be financed as broadly as possible, much like Social Security and Medicare, and assist families, not replace them. Pennsylvania is struggling with this issue, but it is bigger that one state can handle. We must seek a national solution.

The case for a national solution surely was dramatized by the individuals and families you've heard from today. As they attest, it is an issue that is not going to go away. Let me summarize why.

1. Advances in medical technology have made it possible for people to survive traumatic births, accidents and acute and long term illnesses. While many who survive recover fully, many do not and require years of care, and their numbers are increasing.

2. We are an aging population, and with advanced age, we are more likely to need assistance. In 1989, it is estimated that 7.1 million elderly Americans are disabled and need long term care. By the year 2000, this number will grow to 8.9 million, and by 2020 to 12.3 million. In addition, the most rapidly growing group of seniors is those over 85 years, who need long term care perhaps the most.

3. This issue is not just about the elderly. It is estimated that by the year 2000, 40 percent of functionally dependent Americans will be under 65 years. For the adult disabled person, home attendant care is the key to their independance and their ability to participate in school, work and recreation.

4. The financial strain of a long term illness on an individual and/or family can be devastating, and few families can prepare adequately, as you have heard. Insurance coverage (government or private) for hospitalization is usually available. Coverage for long term care, however, is very limited and in some instances nonexistent.

Private long term care insurance currently covers about 1 percent of all long term care. This is because it is outside the realm of possibility for the majority of Americans. Policies are expensive, restrictive and often do not provide adequately either for nursing home care or home care. Where coverage exists, there is a limitation which frequently is quickly exceeded and then benefits cease. In a recent study, Consumer Reports could find no "Best Buys" in the private insurance market.

As for public programs, Medicare covers less than 2 percent of nursing home costs and no long term home care. Medicaid covers about 42 percent of all nursing home care and only limited home care. Many persons using Medicaid for nursing home coverage, in particular, are not poor to begin. They are forced to "spend-down" their life savings and assets in order to use the program, leaving a spouse impoverished.

While there are a number of other public home care programs available through the Pennsylvania Departments of Aging and Public Welfare, unfortunately the growing need for care exceeds available resources. In some areas of the state, long waiting lists exist.

As for private payment, out of pocket, cost is overwhelming, amounting to approximately $35,700 a year in 1988 for nursing home costs. One woman told me that her family was spending $7,000 per month when both her parents were in a nursing home. The cost of home care, which is generally provided on a part time, intermittant basis to supplement the care provided by families and friends, can cost between $45 and $60 per visit and from $25 to $200 per day. A further complication for families is that the need for long term care often presents itself when they have responsibilities for young or teenaged children. This puts them in a position of having to choose between responsibility to their parents or their children.

5. Business, too, is being affected. By the year 2000, the shrinking U.S. workforce will be predominately dependent upon women and other minorities. Women traditionally have been the primary caregivers, and that is not expected to change.

Without help, balancing work and caregiving can result in absenteeism, anxiety, personal illness, and decreased productivity. A resolution, therefore, is not about entitlement. It is a bottom-line issue. Our ability to compete in a global economy is at stake.

These, then, are some of the key reasons why long term care is a family issue whose time has come -- an issue which is begging for a solution. Families are faced with mom and dad or a chronically ill child or adult needing care and little help available.

There are a few other concerns that I want to raise. Quality assurance -- in home care, nursing homes, or other facility-based services, -- must be viewed as a top priority in whatever program is developed.

Home care is provided outside the public eye, often to the most vulnerable among us: people who are sick, dependent, and unable to monitor their own care and ensure that it is of acceptable quality. In addition, there has been an unprecendented increase in the number and types of home care agencies, many of which are not regulated by law. There also has been an increase in the number of self-employed individuals providing in-home care. To safeguard the consumer, all in-home providers should be licensed. At the same time, a consensus must be reached on acceptable standards for training of all home care workers and provision of all home care services -- standards that consumers and payers will recognize as assuring a quality service.

Likewise, standards of care must be agreed upon for nursing homes and other facility-based services, including the training and supervision of their employees who provide care.

Another factor that is currently affecting quality is the acute shortage of qualified long term care workers. Congress should provide a climate which assures access to training and fair wages. A long term care program cannot function without adequate numbers of qualified personnel.

CONCLUSION

I'd like to end my comments on a personal note. My own family has been affected by this issue. My father lost first one leg, then a second leg to gangrene, secondary to diabetes. He learned to walk again on two prostheses. My mother, brother, sisters and I -- but especially my mother -- took care of him. He remained at home until one morning when he laid back on his bed, which we set up for him in the living room, and died peacefully. Just three years later, my mother's health suddenly began to fail, and she was hospitalized. Sadly, she could not go back home. All of us had to work in order to meet our own family responsibilities, and she could not afford to pay for home care, which was what she needed to stay home. In the nursing home, she deteriorated rapidly and had to be readmitted to the hospital. She was subsequently discharged once more to the nursing home where she deteriorated again. She died shortly thereafter.

My parents were proud, working people all their lives -- my father as a farmer and my mother as a factory worker and domestic. They struggled from pay check to pay check, but met their obligations to their family and to their country. In the end, they could get institutional care, but my mother, in particular, was discriminated against because of her need. Home care was what she should have been able to receive, but it wasn't available. Purchasing private long term care coverage or paying out-of-pocket was out of the question. This is their story and, in turn, part of my story. I tell it only to reiterate once more that the system we have in place -- particularly for long term care -- is not adequate. We must do better.

As a nation, we have always counted on our families to take care of one another. When they have needed help, we have stepped in. An ever increasing number of American families need the help of government once again. Eighty-four percent of those surveyed in a 1989 national poll by Lou Harris and Associates said they support a national long term care program for the elderly and disabled. Concern is being expressed by some, however, that it will be too expensive in light of our budget deficit and other priorities. And, some members of Congress point to what happened to the Catastrophic program.

Our response to that is: Catastrophic didn't cover long term care, and, yes, we know that what we are requesting is going to be a major commitment. But we cannot use Catastrophic or the budget deficit as a reason not to act. The need for long term care is not going to go away; we cannot hide from it. It demands action now. We must find a way, and I believe that we will. We are a resilient and resourceful nation. In this century alone, there are countless examples of what we've been able to do when we've put our minds to it. We are prepared to do our part, and we are counting on you, Senator Heinz, and the other members of the Pepper Commission and the Congress to help us.

We look forward to working with you.

Senator HEINZ. Mary Kay, thank you very, very much.
Adele Hebb.

STATEMENT OF ADELE HEBB, PRESIDENT, COMMUNITY HOME HEALTH SERVICES, PHILADELPHIA, PA

ADELE HEBB. Senator Heinz. Mr. Balog, thank you for the opportunity to testify today. It is obvious that you are a caring and listening Commission.

My name is Adele Hebb. I'm the President of Community Home Health Services. Community Home Health Services is Philadelphia's voluntary home health agency. We're also known as the Visiting Nurse Association.

We have a mission of providing home care to all people who need it and of taking care of those who cannot afford to pay for it themselves, as well as those who are covered by various forms of insurance.

We have struggled to raise funds to care for as many of the indigent as possible. The need is far greater than our capacity.

In addition, we have a mission to provide research, education, and advocacy for home care. I am here today as an advocate for home care.

In the last decade, we have provided service to over 100,000 families. Every day we see examples of the scandalous effect of mismatched, ill-considered, and uncoordinated Federal and State policies—policies creating holes rather than providing safety nets.

These policies impact two levels of care, both of which involve long-term care for people at home.

One is recognized by the name, "intermittent skilled visits." These are typical Medicare-supported brief home visits by nurses and other health care personnel. They provide complex and advanced care under medical orders of the patient's physician.

The other, which is less technically advanced but still requires very stringent training and quality control, is variously known as personal care, custodial, or support services.

Some of our patients need intermittent care, some need support services, many need both.

It has been demonstrated often that home care is cost-effective. It is amazing to me that the system is not designed to give more incentives for it.

Senator HEINZ. Linda Rhodes in her prepared testimony has a very good example of that, too—what appropriately delivered health care can do in terms of cost efficiency.

ADELE HEBB. The difference in costs between institution-based care and home care is tremendous. We need to be sure that people are approriately placed.

Charles Daly spoke movingly of people ready to be discharged but stuck in acute care hospitals because there is no place to discharge them to. I would like to continue from that point. Nursing homes which do not have space to take some of his subacute patients have many, many people in them at public expense who could be in their own homes and who would prefer to be in their own homes. I think if you asked the audience here, would they rather have the same tax dollars spent on helping them in a nursing home or in home care, they would unanimously come out for home care.

Also, home care is a way in which we can supplement the natural, free caregiving system, instead of replacing it: Your concern for the economies of health care should certainly be focused on making the most use of willing families and friends, by providing the essential support necessary to make it possible for them to carry out their caregiving functions.

The problem is financial access. It is almost wholly financial access.

In the case of intermittent skilled home care, I think you are well aware of the restrictions on Medicare-covered services imposed or threatened by the actions of the Federal administration. The Congress has responded to preserve the Medicare benefit for home care. We endorse what you're doing and urge you to keep it up. However, Medicare is only one small piece of the problem.

For people who are not eligible for Medicare and who require skilled visits, the Federal Government distributes its support through the States in the form of Medical Assistance and does not require any level of support as a floor for that State Medical Assistance.

We in Pennsylvania are tremendously disadvantaged by that.

We are surrounded by States in which Medical Assistance is reasonably close to the cost of care. Poor people in those States who are dependent on Medical Assistance can access the care they need.

In Pennsylvania, Medical Assistance is a disagrace. It pays roughly half the cost, leaving most Medical Assistance patients in great difficulty finding a source of care. This matter is worthy of your attention. The access to care for patients on Medical Assistance should not be an accident of what State they live in. Federal Medical Assistance funding should assure that States use it properly and give sufficient funding to enable Medical Assistance recipients to get good care.

I have spoken so far about intermittent skilled care and the gaps in that area. But if there are gaps in skilled care, support services are a chasm for anyone who is either poor or in middle income. It is virtually impossible to access a decent amount of support services and personal care.

You've heard many cases today. I would just like to touch on one family among the hundreds whom we've served who has asked me to tell their story.

James and Eleanora Holloway are patients. Eleanora has diabetes and she had a stroke some years ago. She's severely handicapped mentally and physically and her caregiver is her husband, James. He is now 77. He was diagnosed a year-and-a-half ago as having inoperable cancer. His physical condition is deteriorating. He's under our care and when he is out of the hospital, he can barely take care of himself, let alone his wife.

Their daughter, Betty Smith, who is a nurse, is spending all the time that she isn't working trying to take care of her parents, and there are no funds.

They have bartered a room in the house for a lady who will live in and try to give some care, but she's not under supervision; she has not been trained. She does what she can to keep Eleanora safe.

James is coming to a point where his condition is temporarily stablized and we, under Medicare regulations, are required to terminate his intermittent skilled care.

Betty has promised her parents that she will not put them in a nursing home, but it becomes a promise that she sees less and less chance of being able to fulfill.

As a family eligible for Medical Assistance, they would be eligible for nursing home care but not for home care, because they are so-called "custodial" cases.

What can be done about this kind of problem and several other problems I've dealt with?

I would recommend the following to you:

In addition to having a congressional floor placed under the use of Medical Assistance for intermittent skilled home care, I would urge you to consider developing incentives for private affordable insurance products for home care support services.

I have for some years sought a home-care policy for myself. I am willing to pay for one. I cannot find one. There is none that is worth buying. It seems to me that the Federal Government will need to give the insurance industry some incentives to get into what is to them a scary field.

Second, I would urge that the Federal Government, in giving the States funds for nursing home support under Medical Assistance, require them to facilitate diversion to home care.

Right now, the reimbursement system favors the more costly, less desired institutional care over home care.

I would like to see any person who has been assessed by State agencies as eligible for Medical Assistance in a nursing home to have the option to go to any properly certified home care agency for the same level of support. This can be done.

To my knowledge, it has not yet been tried without cumbersome and costly administrative management. We need models which minimize unnecessary and duplicative management. We need to allow families to exercise the option of direct access to homecare at the same level of support available to them for nursing home coverage.

To force them into nursing homes rather than facilitate their choosing home care is a problem that I think this Commission can directly address.

As you look for a system of comprehensive health care, I ask you to consider making home care a central issue and not an afterthought as it has been in the past.

[The prepared statement of Adele S. Hebb follows:]

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Adele S. Hebb
President

Testimony of
Adele S. Hebb, President
Community Home Health Services
Before
The Pepper Commission
Philadelphia, Pennsylvania
November 13, 1989

Thank you for the opportunity to testify today. My name is Adele Hebb. I am President of Community Home Health Services. Our organization is the operating successor to The Visiting Nurse Society of Philadelphia. We are a voluntary, nonprofit organization and the largest provider of home health care in our community. Our mission includes providing the highest quality home care to people of all income levels. We are also involved in education, research and advocacy for home health care.

We provide care in the homes of approximately 10,000 patients each year. We have served over 100,000 family units during the decade of the 1980s. Most of these families are or were coping with catastrophic illnesses or injuries. For some this means a period of several weeks or months; but for more it is a matter of many months, sometimes years.

Most of our clients are homebound and need two levels of care during this period of extraordinary stress.

One level of home care is -- to use the professional jargon -- "intermittent skilled home care". This involves visits in the home by a registered nurse, physical or other rehabilitation therapist or a combination of several disciplines, sometimes assisted by para-professional aides-all under written medical orders from a physician. The intensity and duration of intermittent skilled home care vary with the patient's medical needs. Typically, visits must be made several times each week up to an hour or two at a time, sometimes more frequently, until the medical condition is stabilized.

Intermittent skilled home care is increasingly complex, highly technical and expensive -- but its expense is only a fraction of what it would cost if delivered in a hospital -- and a hospital is where many of our patients would be without this level of home care.

The second level of home care does not require highly trained professionals. The patient needs help with activities of daily living -- light housekeeping, meal preparation, bathing, personal care. In our jargon, that's "private duty care" or "extended care" or "supportive service". Whatever the phrase, the care providers are surrogates for family members. They need some training, but more than that they need to be reliable, kind, and persistent. They need to feel empathy, demonstrate grace under pressure, use common sense and tolerate frustration. This kind of care could be delivered exclusively by friends and family if it were practical, but usually it isn't -- not day in and day out for long periods of time. This kind of care is also expensive; but the alternative -- institutional care -- is equally or more expensive and, as we all know, institutional care is not what most of us want for ourselves or our loved ones.

Often, our patients need both levels of home care during our service. Here is an all too common example from our current caseload:

Mr. James Holloway, now 77, had taken care of his wife Eleanora, for many years. She is a diabetic and stroke victim who is mentally and physically disabled. In 1988, Mr. Holloway himself became seriously ill with an inoperable cancer. He has been in and out of the hospital several times in the past 18 months. While home, he has been barely able to care for himself, no less care for his wife. Both have needed our skilled nursing and other professional care at home.

The Holloways have a daughter, Betty Smith, who is herself a nurse. Betty has to work. When not working she has tried to take care of her parents herself as best as she could. She has no funds to pay for private care. Instead, she found a young woman, with a child, with whom she has bartered -- free room in exchange for at least seeing that her mother is kept safe. But now, with her father declining rapidly, he is need of one-to-one care. He's not eligible for it under Medicare. He is considered "chronically ill", in need of "custodial care." Medicare does not pay for this. Betty Smith had promised her parents never to admit them to a nursing home. She may now have no other alternative.

If our patients are qualified for Medicare, our intermittent skilled care is -- within increasingly restrictive limits -- reimbursed on a cost basis. If the patient is on Medicaid or uninsured, there is a significant gap in the system. I'm proud today that our costs for delivering intermittent skilled care visits are among the lowest in our area. Nevertheless, we are losing between $20-$30 on each skilled visit we make to poor patients on Medicaid. Medicaid reimbursements for home health care in Pennsylvania are among the lowest in the nation. Since our mission includes providing as much medically-necessary skilled care to poor people as possible, we raise funds from a coalition of private sources -- foundations, corporations and individuals -- to subsidize this care. But we cannot raise enough to close a gap which is widening each year; and the sad fact is that while demand increases, the actual number of visits we can afford to make to the poor has decreased in recent years.

If there is a <u>gap</u> in financing the skilled home care component of the long term care system, there is a <u>chasm</u> in the area of extended care services. We offer the services at competitive fees, but many of our families cannot afford them in the quantities they need and patients on Medicaid cannot afford them at all. And we cannot afford to offer them on a charity basis because this would dilute our ability to subsidize indigent skilled care -- where, as I have already explained, we are not meeting the needs in our community.

What can be done to place home care in its proper place as a central solution to the challenge of providing for long term care?

In the area of intermittent skilled care, Congress should establish a national floor for Medical Assistance reimbursements so that access to medically-necessary home care is not a function of where a poor person happens to live. Many states have Medicaid reimbursements based on Medicare-type formulas so that reimbursements approach the cost of providing care. Pennsylvania does not. Pennsylvania and all states should.

Extended care is more difficult. We need a financing system that complements rather than replaces the use of volunteers and family supports. If there is to be a role for the commercial insurance industry, there needs to be incentive to develop affordable products focussed on reasonable levels of home care. For the poor and near-poor and perhaps for all of us, some type of public financing is inevitable and necessary, in my opinion. There are models deserving careful study at the federal level. They include a demonstration program of which we have played a part in Philadelphia for several years. It requires a person to be certified as eligible for institutional placement, but then provides an array of social and health related services to maintain that person at home, at costs lower than in institutional settings.

Home care is what most of our citizens want most of the time. It is safe, more comfortable and, if carefully designed, cheaper than other options. The current non-system of long term care drains the emotional and financial resources of our families and encourages dependency. It is a threat to us all. I hope that your recommendations will focus on evolving a national home care policy at the center of a system of long term care for our citizens.

Senator HEINZ. Thank you very much.

Don English, we're delighted to have you here. It wouldn't be right to have a hearing without you here.

STATEMENT OF DONALD ENGLISH, PRESIDENT, ACTION ALLIANCE, PHILADELPHIA, PA

DONALD ENGLISH. Thank you.

Senator Heinz, members of the Pepper Commission and Aging Committee and ladies and gentlemen here, as has already been said, my name is Donald English and I'm President of the Action Alliance of the Senior Citizens of Greater Philadelphia. Action Alliance is a coalition of 320 senior citizen centers and we're representing over 130,000 senior citizens in the metropolitan area. As you know, many of them are here today, for sure.

Senator, to let you know, I, too, will cut off some of the testimony I have because the time is short.

Senator HEINZ. Without objection, Don, we'll put it all in the record.

DONALD ENGLISH. Thank you.

The need for long-term care is extreme and growing. In 1989, it's estimated that over 7 million elderly Americans are disabled and will need some long-term care. By the year 2000, this number will grow to maybe 8 million or a little over.

Now, we know that one person in two above the age of 65 will spend some time in a nursing home in their life and one in four will spend a year or more.

By the turn of the century, the nursing home population, we think, is expected to grow about 37 percent.

So, long-term care is not just a concern for the elderly or the disabled person, but it is a concern for the entire family, young and old alike, and as the first panel showed, the costs and responsibilities are borne by the family whenever it is possible.

In 1987, families paid out-of-pocket 51 percent of the costs for nursing home care which amounted to over $21 billion. A much higher toll of money, time and commitment went into long-term care in the home and the community settings.

I ask this question:

Why is the private long-term care insurance inadequate?

First, the coverage offered by most policies is very narrow and second, the cost of this insurance is unaffordable except for the very, very rich.

Quoting a term from James Firman and William Weissert, they indicated in their report, Private Long-Term Care Insurance: How Well Is It Meeting Consumer Needs and Public Policy Concerns? "Most long-term care policyholders who enter a nursing home will never collect any benefits" because the policies have many restrictive conditions which exclude most people's long-term care situations. They explained that "Long-term care plans which offer $50 per day in coverage (the most common type of nursing home coverage) are grossly inadequate to meet the expected costs of care." These policies don't pay for many of the services which are needed and rendered. Their study also showed that 56 private insurance plans and options in which home care benefits were offered found

"—substantial restrictions (or limitations) that make it unlikely that most persons in need of home care will collect significant benefits." In some cases, restrictions on coverage exclude as many as 90 percent of the policyholders with long-term home care needs.

Robert Paul and Thomas N. Bethell will point out in their Case for a National Long-Term Care Insurance Policy that only a very small percentage of people can afford a long-term care policy.

As indicated above, most popular current policies will never provide the benefits for which people purchase them and yet only a few can afford these inadequate policies. Better policies cost much more. Policies which will provide quality comprehensive coverage would be prohibitively expensive through private insurance for most older people.

As we all know, Medicare coverage of long-term care is pitifully inadequate. Even the expansion provided in last year's Catastrophic Protection Act, Medicare still covers just a tiny fraction of the elderly's long-term care needs.

The final alternative currently available is Medicaid, but although Medicaid pays billions of dollars for long-term care services, its coverage is inadequate and it's requirements demeaning.

First, Medicaid provides little or no coverage for in-home or community services, forcing people into nursing homes when they would prefer to remain at home, as already has been stated, where care would often be more private and almost always less expensive.

Second, Medicaid-eligible patients applying for nursing home admission in Philadelphia are unable to get into the better nursing homes, leaving us with a nursing home system that is segregated along racial and economic lines.

Medicaid regulations that require a person and his or her spouse to impoverish themselves in order to get assistance are cruel, inhumane, and demeaning.

Although there have been some improvements as a result of the Medicare Catastrophic Protection Act, people must still deplete most of their assets and spend down their income to a ridiculously low level in order to qualify for Medicaid benefits. As a result, Medicaid helps fewer people than it should and causes unnecessary suffering and pain to people needing its aid.

In Pennsylvania, many people have custodial care needs due to forgetfulness and wandering but who are physically healthy as a horse.

Boarding homes will not take them because they need 24-hour attention which is too expensive to provide.

A nursing home won't take them because Pennsylvania Medicaid refuses to pay because there is no medical illness that requires nursing care.

Therefore, the person is left without the needed supervision. Nevertheless, attendant care for lack of mental capabilities is required and this is a severe limitation of Medicaid with respect to long-term care.

In short, Medicare, Medicaid, and the private sector do not meet the needs of single senior citizens who are all alone, the poor, working and middle class families who want long-term care aid without becoming impoverished.

The second point I would like to make is that opinion polls show that Americans are willing to pay more in taxes for services, as you've heard today, that they believe will meet the human needs. Further, these polls show that long-term care is consistently cited as a No. 1 priority for increased Government spending and that respondents believe that families must be protected against the costs of long-term care.

There exists today the desire to pay for a public plan for long-term care. People believe that if funded and managed with the efficiency and effectiveness of Social Security and Medicare that a national long-term care plan will work well.

Finally, let me share just a few thoughts on how a long-term care program should be structured and financed.

Action Alliance is a member of the Pennsylvania Long-Term Care Campaign and we have endorsed their 10 principles that should govern a national long-term care program. These 10 legislative principles are attached, but I want to discuss several key ones for just a moment.

First, a long-term care plan should be universal, available to all citizens regardless of age and income. Eligibility should be based on physical, mental, medical, and behavioral limitations and the need for support or training, not one's age or how much money one has. Further, any Federal long-term care program must treat all persons the same, regardless of income. We must have the same level of care, the same delivery system, the same quality of care for all citizens. No two- or three-tiered system is fair or acceptable.

Second, a national long-term plan should provide a comprehensive range of institutional, in-home and community-based health, social, and support services. Services should be provided in such a way as to maintain independence, allowing a person to remain in the community and the setting preferred by the patient and the family. We underscore that.

Third, the financial risk for long-term care should be spread as broadly as possible through a universal social insurance program like Social Security. This would reduce the cost per person and ensure that the burden of payment will not be insurmountable on the victims alone.

Among the possible funding mechanisms are lifting the cap on earnings subject to Social Security taxes above the current $48,000 ceiling as proposed by the late Representative, Claude Pepper. This would not only raise funds for long-term care, but would make the Social Security system more progressive.

Let me emphasize that co-payments and deductibles punish the sick and injured and should not be used as a way to finance the program.

Today in Medicare, seniors pay out-of-pocket as great a percentage of their income for health care as they did before Medicare started in 1965. Most of this is due to constantly increasing co-pays and deductibles.

Also, the level of funding must be sufficient to meet the needs without waiting lists and unmanageably large caseloads. Services need to be available in reality, not just on paper.

In closing, let me add that a long-term care system in no way lessens the need for a comprehensive national health-care system to replace our ineffective, wasteful, overly expensive current health-care system.

The Pepper Commission should report to Congress a complete national health-care program which includes long-term care and which provides quality, affordable health care and long-term care to all Americans. We can no longer afford the excessive profiteering by insurance companies and health-care providers inherent in our present system and we simply cannot tolerate the unnecessary suffering of millions of Americans, young and old alike, who cannot afford the health care they need.

It's time for a reordering of our national priorities, to place the premium where it should be, on human needs.

It's time for drastic cuts in a bloated military budget and for a return to a progressive tax system, not a capital gains cut.

It's time for the United States to leave the company of South Africa and to join with the other industrialized nations of providing national health care and long-term care to all our citizens.

We can afford it, and I emphasize, we can afford it, if we put our priorities in order and more importantly, we simply cannot afford the pain and suffering that our current policies cause.

Senator Heinz and Mr. Balog, it is time for action. In memory of the valient crusader whose name you bear, I urge the Pepper Commission to launch and lead the crusade for national health care and national long-term care.

Thank you.

[The prepared statement of Donald English follows:]

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Testimony to the Pepper Commission and the Senate Select Committee on Aging Monday November 13, 1989

Good morning!

Senator Heinz, members of the Pepper Commission and Aging Committee, ladies and gentlemen: My name is Donald English and I am President of the Action Alliance of Senior Citizens of Greater Philadelphia. Action Alliance is a coalition of 320 senior citizen clubs and centers, representing over 130,000 senior citizens in the metropolitan area. Many of them are here today, as you can see.

On behalf of our members, I thank you for bringing a field hearing to Philadelphia and allowing us to address these issues. During the next few minutes I would like to deal with 3 main issues: the need for long term care, the strong public support for it, and some suggestions on how a national program should be structured and funded.

As you've heard from other panelists today, the need for long-term care is extreme and it is growing. In 1989, it is estimated that 7.1 million elderly Americans are disabled and will need some long-term care; by the year 2000, this number will grow to 8.9 million. One person in two above the age of 65 will spend some time in a nursing home during their lives; one in four will spend a year or more. By the turn of the century the nursing home population is expected to grow 37%.

Long-term care is not just a concern for the elderly or disabled person; it is a concern for the entire family. As the first panel showed, the costs and responsibilities are born by the family whenever possible. In 1987 families paid out-of-pocket 51% of the costs for nursing home care, which amounted to $21.2 billion. A much higher toll of money, time and commitment went into long-term care in the home and community settings.

But although this care is critically needed, neither private insurance, Medicare or Medicaid meet families' long-term care needs.

Why is private long-term care insurance inadequate? First, the coverage offered by most policies is very narrow; and second, the costs of this insurance is unaffordable except for the few very rich.

As James Firman and William Weissert indicated in their report "Private Long Term Care Insurance: How Well Is It Meeting Consumer Needs and Public Policy Concerns?": "Most long-term care policy holders who enter a nursing home will never collect any benefits" because the policies have many restrictive conditions which exclude most people's long-term care situations.

They explained that "long-term care plans which offer $50 per day in coverage (the most common type of nursing home coverage) are grossly inadequate to meet the expected costs of care." These policies don't pay for many of the services which are needed and rendered. And their study of 56 private insurance plans and options in which home care benefits were offered found "substantial restrictions (or limitations) that make it unlikely that most persons in need of home care will collect significant benefits." In some cases, restrictions on coverage exclude as many as 90% of the policy holders with long-term home care needs!

Robert Ball and Thomas N. Bethell point out in their "Case for a National Long-Term Care Insurance Policy" that only a very small percentage of people can afford a long-term care policy. As indicated above, most popular, current policies will never provide the benefits for which people purchase them; and yet, only a few can even afford these inadequate policies. Better policies cost much more. Policies which will provide quality, comprehensive coverage would be prohibitively expensive through private insurance for most older people.

As we all know, Medicare coverage of long-term care is pitifully inadequate. Even with the expansion provided in last year's Catastrophic Protection Act, Medicare still covers just a tiny fraction of the elderly's long-term care needs.

The final alternative currently available is Medicaid; but although Medicaid pays billions of dollars for long-term care services, it's coverage is inadequate and its requirements demeaning. First, Medicaid provides little or no coverage for in-home or community services, forcing people into nursing homes when they would prefer to remain at home, where care would often be more appropriate and almost always be less expensive. Second, Medicaid-eligible patients applying for nursing home admission in Philadelphia are unable to get into the better nursing homes, leaving us with a nursing home system that is segregated along racial and economic lines.

Medicaid regulations that require a person and his/her spouse to impoverish themselves in order to get assistance are cruel, inhumane and demeaning. Although there have been some improvements as a result of the Medicare Catastrophic Protection Act, people must still deplete most of their assets and spend-down their income to a ridiculously low level in order to qualify for Medicaid benefits. As a result, Medicaid helps fewer people than it should and causes unnecessary suffering and pain to people needing its aid.

In Pennsylvania many people have custodial care needs due to forgetfulness and wandering, but who are physically healthy as a horse. Boarding homes will not take them because they need twenty-four hour attention, which is too expensive to provide. A nursing home won't take them because Pa. Medicaid refuses to pay because there is no medical illness that requires nursing care; therefore, the person is left without the needed supervision. Nevertheless, attendant care for lack of mental capabilities is required. This is a severe limitation of Medicaid's with respect to long-term care.

In short, Medicare, Medicaid and the private sector do not meet the needs of single senior citizens who are all alone, the poor, working and middle class families who want long-term care aid without becoming impoverished.

The second point I would like to make is that opinion polls show that Americans are willing to pay more in taxes for services that they believe will meet their human needs. Further, these polls show that long-term care is consistently cited as a number one priority for increased government spending and that respondents believe that families mus be protected against the costs of long-term care.

A 1987 survey for Time Magazine showed that nearly 66% of middle-aged and older citizens prefer a government social insurance program for long-term care, as opposed to a private program with government involvement only for the poor. A 1987 poll for AARP found that nearly 70% would pay for specific additional taxes for a government long-term care program. And 80% said in this AARP poll that any long-term care program should cover all family members not just the elderly.

There exists today the desire to pay for a public plan for long-term care. People believe that if funded and managed with the efficiency and effectiveness of Social Security and Medicare that a national long-term care plan will work well.

Finally, let me share just a few thoughts on how a long-term care program should be structured and financed. Action Alliance is a member of the PA. Long-Term Care Campaign and we have endorsed their 10 principles that should govern a national long-term care program. These ten legislative principles are attached, but I want to discuss several key ones for just a moment.

First, a long-term care plan should be universal, available to all citizens regardless of age and income. Eligibility should be based on physical, mental, medical and behavioral limitations, and the need for support or training; not one's age or how much money one has! Further, any federal long-term care program must treat all people the same regardless of income. We must have the same level of care, the same delivery system, the same quality of care for all citizens. No two or three tiered system is fair or acceptable.

Second, a national long-term care plan should provide a comprehensive range of instutional, in-home and community-based health, social and support services. Services should be provided in such a way as to maintain independence, allowing the person to remain in the community and the setting preferred by the patient and the family.

Third, the financial risk for long-term care should be spread as broadly as possible, through a universal social insurance program like Social Security. This would reduce the cost per person and ensure that the burden of payment will not be insurmountable on the victims alone.

Among the possible funding mechanisms are lifting the cap on earnings subject to Social Security taxes above the current $48,000 ceiling as proposed by the late Rep. Claude Pepper. This would not only raise funds for long-term care but would make the Social Security system more progressive. Other options are increased inheritance taxes at death or enacting dedicated personal and corporate taxes. Remember that polls have shown that the public will support taxes dedicated to human services they know will protect their families in times of need.

Let me emphasize that co-payments and deductibles punish the sick and injured and should not be used as a way to finance the program. Today in Medicare, seniors pay out-of-pocket as great a percentage of their income for health care as they did before Medicare started in 1965. Most of this is due to constantly increasing co-pays and deductibles. Also, the level of funding must be sufficient to meet the need without waiting lists and unmanageably large caseloads. Services need to be available in reality, not just on paper.

In closing, let me add that a long-term care system in no way lessens the need for a comprehensive national health care system to replace our ineffective, wasteful, overly expensive current health care system!

The Pepper Commission should report to Congress a complete national health care program which includes long-term care and which provides quality, affordable health care and long-term care to all Americans. We can no longer afford the excessive profiteering by insurance companies and health care providers inherent in our present system; and we simply cannot tolerate the unnecessary suffering of millions of Americans, young and old alike, who cannot afford the health care they need.

It is time for a re-ordering of our national priorities to place the premium where it should be: on human needs. It is time for drastic cuts in the bloated military budget and for a return to a progressive tax system (not a capital gains cut)! It is time for the United States to leave the company of South Africa and to join with the other industrialized nations by providing national health care and long-term care to all our citizens. We can afford it, if we put our priorities in order. And more important, we simply cannot afford the pain and suffering that our current policies cause.

Senator Heinz and members of the Commission, it is time for action. In memory of the valiant crusader whose name you bear, I urge the Pepper Commission to launch and lead the crusade for national health care and national long-term care!

Thank you.

Senator HEINZ. Don, they'd almost like you to do an encore, but on another occasion. You were really on a roll. I haven't been interrupted that many times for applause in all the speeches I've given in 15 years combined.

DONALD ENGLISH. Thank you, Senator.

Senator HEINZ. I know that Jim Dorsch who represents the Health Insurance Association of America is probably wondering why we invited him here after one particular comment you made in your third to last paragraph about insurance companies, but that's what fairness is all about.

Jim, we want to thank you for coming up here from Washington.

Our last witness on this panel is, indeed, Jim Dorsch who is the general counsel of the Health Insurance Association of America, if I've got that right.

STATEMENT OF JAMES DORSCH, WASHINGTON COUNSEL, HEALTH INSURANCE ASSOCIATION OF AMERICA

JAMES DORSCH. That's correct, Senator, and it is really an honor to be invited up here. It was a privilege to listen to your panels today because there are so much that we do agree with, even though we do take some respectful disagreement perhaps with at least the last witness.

This is a problem that affects us all and, as so many of your witnesses have said, we are all in it together.

My own mother, for instance, did, in fact, die after several years in a nursing home in 1972. So, we do all know firsthand the problems and we all want to be part of the solution and that includes the insurance industry and the men and women who make up the insurance industry.

It is true that long-term care is, in fact, the hole in the Nation's economic safety net for the elderly. Secretary Bowen of HHS in his report to the President on catastrophic illness in November 1986 said at that time that 500,000 middle-class Americans a year spend down into Medicaid for nursing-home care, that more than half the Medicaid dollars spent in the country went, not for medical care for poor families, for poor children who desperately need it, but for middle-class Americans who are spending down on nursing home care.

I think the key question comes, how can we help middle-class Americans finance their own long-term care so that we can use hard-earned tax dollars for the people who so desperately need them, as in many of the cases that we have heard?

Long-term care insurance is one of the most rapidly changing types of insurance that America has seen in many, many a decade. It is very much in flux.

I have to make a comment as to the bloated profits. It's hard to have bloated profits when you have so few sales. It's a very new product and that's one of the problems and one of the things I want to get to.

The question is, is private health insurance available now, not 10 years ago or 5 years ago, and the answer is, yes.

In 1984, there were only a handful of companies, maybe 16 insurance companies, selling long-term care insurance; there are now over 100 insurance companies selling long-term care insurance. Over a million-and-a-half persons have purchased long-term care insurance in the country today. Most of that is in the last year or two.

Again, I can tell you a personal experience; a year ago, in Marshalltown, IA, my financee's parents, Milo Pitcher was 80 years old; his wife Elsie was 79. He died of bone cancer. Elsie Pitcher saw the need to look after her own future; so, she asked her daughter for help—her sons and daughter.

Virginia came to me for help and I had a chance to find out whether the system really works, whether all the things that we're saying are true; is long-term care insurance available or isn't it?

So, to see if the system works, I took her a copy of our consumer's guide for long-term care insurance and a list of the insurance companies that were by now selling in Iowa. We sent it off—to see if the system works, and, by golly, it did.

It was a very interesting thing; Elsie Pitcher, 79, in Marshalltown, IA, bought a policy which provided 1 year's care with first day coverage, and her kids jumped all over her. They said, "Mom, that's not what you need. We're worried about your long-term care if you're in a nursing home for a number of years."

She had this hard-headed Midwestern outlook and said, "I've looked at all my friends who have gone into a nursing home, all of them had fallen down and broken a hip or bone and they're always out in 6 months, so this is the best way for me to get my money back."

Her kids grabbed her and said, "Wait a minute; we aren't interested in your getting your money back. We want financial protection if you're in for 4 years, 5 years, or whatever."

She called back the insurance agent who wrote the policy and he put in a waiting period for the first 3 months or 6 months, and for a couple hundred dollars more a year she now has coverage for 5 years. She does have coverage and she is happy with it.

What's happening today that's much more important than that is the beginnings of employee group insurance. We know what that has done with health insurance. Today, 90 percent of the people with health insurance in this country get it through the work place.

In 1988, private health insurance provided $140 billion in medical payments for medical care.

With regard to long-term care insurance, it's just beginning to be offered by major insurers through the work place and it is already available.

In the States of Alaska, Maryland, Ohio, and South Carolina, they offer a long-term care insurance policy to their employees. Proctor & Gamble and American Express are making it available and I found out that as of January 1, 1990, the Health Insurance Association of America, for which I work, is going to be offering long-term care insurance.

I've just received information this week and I would like to give it to you, Senator, for you to look at and for the record, to see what kind of long-term care insurance is available now.[1] This insurance

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[1] See appendix, p. 75.

does, in fact, provide coverage for anyone who loses two of the five activities of daily living; it covers Alzheimer's disease. It takes a doctor's certificate, but if any two of the five activities of daily living are not there, that is, dressing, toileting, eating, transferring, say from the bed to a wheelchair, back and forth, or mobility, the insurance company will pay the benefit. Now, that's regardless of whether it's in a nursing home, whether it's home health services, whether it's respite care, or in the person's own home. It will pay the home benefit even if the care is given by a family member or friend, if the two activities of daily living criteria are met.

The cost will vary tremendously according to your age.

Now, we have also found that among the people who are signing up in this employee group insurance, the average age is 40 years old, which brings down the cost immensely. You can also bring in your spouse or your parents, or your spouse's parents.

Regarding the age criteria that has been mentioned, this is a problem that can hit anyone of any age.

It is available for people down below 25 years old, which is the lowest premium, obviously, or available to those who are more than 90 years old and, obviously, the premiums then are most expensive. So, it is available; it isn't cheap, however, as we all know.

We know that medical care is not cheap. That is one of the great pressing problems facing our country today, the soaring cost of medical care, but what can the Congress do to help?

There are two things which we have been asking the Congress to do and both of those were on Secretary Bowen's list.

One is to clarify the Code, the Internal Revenue Code, to say that long-term care is, in fact, health care, that it's medical care.

In the Code now, if an employer provides health insurance as a benefit, and pays part of the premium, it's not income to the employee and the employee doesn't have any taxable income, the benefit is paid to the hospital or doctor.

With long-term care; it's not clear; it's not mentioned in the Code. So, when our companies go to employers to try and sell this as part of the employee benefit package, the employer says, "What's the tax consequences" and we have to say, "We don't know."

We have asked the IRS for a ruling. We have not gotten one. They haven't refused it, but they haven't clarified it either way.

Secretary Bowen said that this was a top priority. Our industry said that it's a top priority.

If you could put it in, health insurance could be offered as part of a cafeteria plan for those, perhaps, older workers who no longer need life insurance and would prefer to have long-term care insurance, or not as much vacation, or whatever, but it's just not there yet.

The second thing that could be done is to allow a tax-free rollover of current insurance assets into long-term care insurance. By "current assets," I mean life insurance, IRA's, pension, and so forth. Many people in advanced years have paid-up life insurance and would gladly take some of their life insurance benefits early in order to help them in their senior years, either in a nursing home or outside of a nursing home.

There are 103 million Americans who own life insurance today with a face value of $4½ trillion. Now, that's a lot of money that could be used today and that's not 30 years from now, but that could be used now if the law were amended to allow insurance to pay that money for long-term care benefits.

With that, Mr. Chairman, I'll conclude and be happy to take any questions.

Senator HEINZ. Thank you very much, Mr. Dorsch. There may be some customers who are somewhat skeptical; if not, they may be lining up to see you afterwards, but thank you for your very helpful testimony.

One question I would like to ask of Linda Rhodes, who had started this off so very well, has to do with the item in her testimony regarding Pennsylvania's implementation of a pre-admission screening program for all Medicaid-eligible recipients for nursing-home care, and in her testimony she describes how that is saving a lot of money.

What you're finding is you can deliver home care much more efficiently and cheaply and with the same health benefit to the individual than the alternative institutionalization.

My question for you is:

Can you tell me whether and under what circumstances it would be appropriate to require pre-admission screening for private-pay patients?

LINDA RHODES. I think that issue in terms of private-pay, part of that was addressed recently because of OBRA, and you're asking us to screen anyone who has mental health, mental retardation, or developmental disability and the private pay patients are to be screened.

The issue, of course, facing the States is, who's going to pay for the private-pay patient? Should they have to pay to be screened by the State or is this something that the State picks up?

Our answer has been, through the OBRA experience, that we're not charging for that.

There were, I think, two or three States who actually considered it and backed off of it because they didn't feel that it was appropriate.

The problem, I think, with the assessment program has been that right now we're in a position in the State that we're screened about—last year, it was like 13,000 people. We discovered about one out of four were being referred for a higher level of care. Of that number, we were able to serve about 14 percent so they could stay at home, which is something that they wanted. It's not just purely a cost savings issue. The other issue is that we're only in eight different areas in the State where we're also attaching the services with the assessment consignment.

My major concern has been that we're got to be in a position to not just go in and assess someone and say, here's the different services that could be made available to you or here's how you could stay at home, and then there's no one there to help back them and give them some of the services to do that. Unfortunately, in some areas of the State, that's still the position that we're in; when we're looking at it, it would be about a $30 million solution.

Senator HEINZ. Say that again.

LINDA RHODES. I think it's important that we've not just in a position of assessing people, but the problem is that in some areas, we haven't been able to provide the services that go with it and I think we should be doing that for people.

Right now if we we're to make the assessment and services program statewide in Pennsylvania, it would cost us around $30 million.

Senator HEINZ. That was the number that I just wanted to be sure that I heard.

Commissioner BALOG. Excuse me, Senator.

Senator HEINZ. Jump right in.

Commissioner BALOG. $30 billion?

LINDA RHODES. Million.

COMMISSIONER BALOG. Projecting to the nationwide level——

Senator HEINZ. [continuing]. It would be 20 times that much. We're 5 percent of the population.

Commissioner BALOG. OK.

Senator HEINZ. Adele Hebb, in her testimony, I think, puts her finger on a very critical issue which is to design a care system which complements, but does not replace the care given by families and communities.

Linda Rhodes has discovered that people are actually being given a higher level of care than is medically necessary or that they would desire.

How do we do what you want to do which is what I think everybody wants to do? How do we design a system that doesn't result in what Linda would possibly describe as overutilization, if that's not too technical or harsh a word, or in the case of families, underutilization of what is fair for them to give of themselves?

ADELE HEBB. Well, to begin with, I would hope that you would look at a system in which the Federal dollars going to States for Medical Assistance are conditioned on a requirement for nursing home diversion so that people are assessed, and if they are found to be capable of being sustained in their homes at a cost that does not exceed what the nursing home payment would be, to require that the family have that option.

The next step would be to be sure that there are federally certified provider agencies in the communities and I think our Medicare experience has been such that you can rest assured that if there is a system for a reasonable cost payment for home services, there will be agencies available to meet quality assurance standards and deliver it.

I do want to reinforce something Mary Kay said that I think is terribly important. In addressing home care and other modes of care, you must be concerned for quality assurance and certification, particularly the training and supervision of the caregivers.

Senator HEINZ. One of the things that the Commission feels that it is free to do is to totally redesign the American health-care system because we all recognize that there are a lot of very costly customs that have grown up in it.

We've talked seriously about the Canadian system and I think many of us are quite attracted to the Canadian system, except that it represents such a radical departure from the idea that if you have some more money and you want to go outside of the national health-care system, you should be allowed to go to a doctor for additional care. In Canada you can't do that. You go to the Government; you get what they have got, and if you don't like it, you go to Cleveland, literally.

You think about the United Auto Workers and they have got one kind of plan; it may be better than what they have in Canada; I'm not sure.

However, we feel quite free to take a broad brush, as long as we fill in fine strokes, and to recommend an overall system. We may or may not do that.

To go back to the elements of the present system, Linda Rhodes was talking about a better integration, not only of agencies but of the Federal Government and the State Governments, and we have a system that is theoretically designed to do that; it's called the Medicaid Program. It's got all kinds of problems; we all know what they are, but I'm not sure when Medicaid was originally written back in 1964, people intended it to be the way it is now. What has happened is that the constituency of Medicaid is relatively small and very voiceless. As for reimbursement rates under Medicaid, they probably started off okay, but over time, have dwindled down to the point where when you say "Hello, here's my Medicaid card," whoever you're giving it to winces and you're lucky if you get anything approaching what most other people get.

Recognizing those kinds of shortcomings, would it nonetheless be possible, if maybe we changed the name of the program, to start all over again, but to redesign Medicaid so that it starts at a higher level, say 150 or 200 percent of poverty? If we provided for decent reimbursement rates. Whether the match is 50, 55, 60, 65, and as Linda would say, how about 90, it had a Federal-State financial component and a lot of State responsibility for running it.

How much of a solution to the problem of long-term care and access would that be and where would our main problems still be?

Obviously, there would be an assets test problem which I don't think is insolvable. I think you can design around that.

Anybody?

Commissioner BALOG. May I put one more point on it and try to blot out of your mind the stigma of Medicaid as it has been.

MARY KAY PERA. That's a tough problem.

ADELE HEBB. That's the point.

Senator HEINZ. Imagine a renamed Medicaid Program with a much larger constituency.

ADELE HEBB. Essentially, you're talking about, as you should be, a virtually universal health-care system in which the insurance may be directly governmental or may be partly governmental and partly through the private insurance agencies and industry.

Senator HEINZ. Let me ask Don and Maggie because they are the advocates as opposed to the providers.

Obviously, in one sense if we give one reimbursement as a provider, you're not going to complain too much.

It's really Maggie and Don who probably ought to be heard first and foremost on this issue.

Maggie, you go first.

MAGGIE KUHN. We've been monitoring Medicare and we have published the names of the physicians who accept Medicare assignment. Many do not and there is a bias that we feel to be most unfortunate.

Senator HEINZ. That's under Medicaid or Medicare?

MAGGIE KUHN. Medicare. I'm citing the two parallels.

Senator HEINZ. What you're saying, therefore, is that if it doesn't work for Medicare, which reimburses at a much more generous level than Medicaid, you doubt whether Medicaid would work, no matter how we retitle reform.

MAGGIE KUHN. I believe we have got to come to a universal health-care system.

As I said earlier, the time is at hand to adopt it and I think the Pepper Commission and your leadership put us in a forward march toward a new system. You have raised the consciousness of many.

Senator HEINZ. We're working at it.

MAGGIE KUHN. We want to work with you, but moving beyond long-term care to a comprehensive system that involves every American.

Senator HEINZ. Don, what is your comment?

DONALD ENGLISH. I think that's not something that can't be done. One of the things we were talking about, most of the people wouldn't mind paying some percentage, something toward that situation, in order that they will get affordable health care; so, that's something that I think the Commission really needs to look at in terms of an overall.

What happened on this last thing, what happened with the catastrophic plan, we've been talking to many of our older people and they don't see anything wrong with it if we have to pay or the people coming along would have to pay.

This would help solve a lot toward that.

Senator HEINZ. Don, let me at this point ask Jim Balog for any questions he has.

I'm going to have to leave in a few minutes to catch a train and get back and do my other duties in Washington, DC.

Jim, how is your schedule?

Commissioner BALOG. I have a few minutes.

Senator HEINZ. OK.

Commissioner BALOG. I think Ms. Pera mentioned the idea, or at least it came to me when she was talking, that older Americans have to be part of the solution.

We continue to consider them part of the problem.

Unless we consider them as part of the solution, the problem is going to get larger and larger.

To what extent have older Americans been part of taking care of older Americans?

Would you be interested or would it make any sense, an idea I once heard, that perhaps older Americans, those 65 to 70 years old who are still in good health, could get care credits by taking care of other older Americans so if they got to 70 or 75, they would have built up care credits; in other words, work at it when they're able in order to recapture those care days when they get older?

What has happened to the older Americans in taking care of other older Americans?

MAGGIE KUHN. Our view as Gray Panthers, and we are an intergenerational group, age and youth in action, is that health is a basic human right and it ought to be paid for out of public moneys.

We have public education; we pay for schools and we're proud of the fact that we pay for schools.

Health is another basic human right and service and there ought to be taxes supporting it.

We are unenlightened as a society. We are sick as a society when we do not take some basic accountability for our health and well-being from birth to death.

MARY KAY PERA. I think, sir, that the public solution, the public sector, would give us the largest pool if we all pay into it, no matter what our age, just like we're doing right now for Medicare. It seems to me that that is the way.

In terms of seniors taking care of seniors, that's going to happen anyway. That's happening now.

Today, we heard from five people who have used the private sector and it wasn't enough. It just didn't work. In the end, it didn't work, and that's why I think the public solution has got to be the answer.

Commissioner BALOG. It's an insurance program. The premiums are collected in a different way, through taxes on your wages, but still we all chip in to get something out.

MARY KAY PERA. Exactly.

LINDA RHODES. The kind of program that you're talking about, we have seen tried out in a few different areas by older people taking care of older people. I think what the group here is saying is that this is occurring and that kind of solution is somewhat more of a patchwork once again with quite a few problems.

We've also testified in other kinds of hearings that providing care is not a simple matter, and people need to have training.

I know when I cared for my husband's grandmother, I had to learn just how to give her a bath, how to get her in and out of the tub, just the very basic things that you can't expect that all of these families are going to naturally be able to learn how to do.

The other thing we're seeing all the time is where it's the 65-year-old taking care of someone in their nineties. That goes on; that's common; that exists.

The other thing, a newer thing we're discovering with adult day care, is that more and more people are using adult day care, not for respite care; it's because the older person in their fifties or in their sixties, they're working and they need adult day care just as their middle-aged counterparts need it for their children, as well, because they're also working and actually losing income. That is already occurring.

People wouldn't see that as a new solution, older people already taking care of older people.

Commissioner BALOG. OK.

Any other comments?

Any other questions you want to ask of each other from the panel?

Mr. Daly, I have one question of you and that is:

To what extent is the disparity taking place in the cost per day?

For example, in the emergency room, the cost per treatment is going up very rapidly. I understand that in many emergency rooms, the cost of delivering emergency room service is greater than if you're admitted into the hospital. One hears that. Is that true?

Second, what is happening in the disparity in the cost per day, you mentioned, between the Medicare patient and a private insurance patient or God forbid somebody that doesn't have any insurance at all? What is the disparity and what is charged to those people now in the hospital if you take a Medicare and a non-Medicare individual?

Mr. DALY. I believe, Mr. Balog, you're referring to what strikes me as the difference between hospital charges and costs.

Essentially, what I was referring to in my testimony is that there is a cost shifting that occurs. Because of the fact that Federal and State programs underpay, this has the effect of increasing charges under private insurance coverage.

Now, the amount of this underpayment is substantial.

For example, in our State's Medicaid program, we estimate that 50 percent of the costs, not the charges, 50 percent of the costs are paid for by the State Medicaid program for outpatient or emergency care. Approximately 78 percent of costs are paid for on the inpatient side.

This is a real money-losing proposition for hospitals and in order to recoup the substantial losses they have, they have to shift these costs over to the private insurers.

I hope that's responsive to your question.

Commissioner BALOG. I think it's responsive and I think it's indicative of one of the things that are happening.

As other elements of the medical care system don't keep up with their share, the dispartity grows, and more and more people can't afford any kind of insurance. I think it's 31 to 37 million now; it's going to get worse and worse with time.

I've been at this business, public health policy, for 10 years and I see it getting worse and not better for things like this, exactly things like this.

CHARLES DALY. It's a tremendous problem.

Commissioner BALOG. Does anybody have any further question or comment?

MAGGIE KUHN. May I just say one more comment?

The insured system is not the way. We need a reordering of our national priorities and our national budget. We are living with a bloated defense budget that is wasteful and corrupt. We need to take money from the defense budget and transfer it to the humans services, and sustain life, not destroy it.

Commissioner BALOG. Thank you very much.

Of course, we don't serve on the Defense Committee, but I couldn't agree with you more.

MAGGIE KUHN. You could influence the Defense Committee.

Commissioner BALOG. Well, quickly, what's going to influence the defense establishment and the other policymakers having hearings like this all over the country, whether we need an FX1 or FX9 or FX42, is this kind of pressure that has to just keep up.

Our system of government is one of pressure groups. Let's face it. There's one group pushing this way and one group pushing that way.

Somebody once described a Congressman as a man who stands up upright, being pushed at all sides with equal force. He should stand upright and say, "This is right."

We're getting there. This country is getting there as to the question of how we get over this wall of resistance to a solution that's better than the patchwork things that we've had.

There are reasons why we start off with the patchwork system. It took Canada 40 years to get where they are and Canada doesn't have a systematic long-term program even now.

So, it takes time to get there. I know you're all impatient and all that kind of stuff. I'll soon be on Medicare myself and I'm getting impatient, but at least these kinds of hearings, this kind of pressure and this kind of thought is getting us there. I can assure you that the progress toward dealing with these ever-growing problems is pretty good, given our system of government.

We have had this problem on our national agenda for a long time and I hope that what we have done here today and what we're going to be doing over the coming months will at least get us closer to the solution, if not the solution.

Thank you all very much for being with us.

APPENDIX

Item 1

Long-Term Care

benefits

HIAA

Health Insurance Association of America

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HIAA offers protection for you and your family against long-term care costs

Americans are living longer, more productive lives. But longer life does not always ensure good health. For many of us, as life expectancy increases, so does the likelihood that we will require some type of *ongoing* care if age, illness or disability makes us dependent on others.

introduction

Most of us would prefer not to think about the possibility that we—or someone we love—will ever need long-term care. And like many Americans, most of us assume that coverage for such care is already provided under current medical plans or by Medicare. But Medicare pays for only a small fraction of the cost, while Medicaid covers only a portion of long-term care for the poor.

Now, HIAA offers you its Long-Term Care Plan, a new benefit program designed to help you combat the catastrophic financial costs of long-term, custodial-type care. You pay the full cost of participating in this program. Some of the words mentioned in this booklet may be new to you. Please check the Glossary in the back for definitions of key terms used in HIAA's Long-Term Care Plan.

long-term care — what is it?

It's not just nursing home care. It's not just for the elderly.

Long-term care refers to a wide range of personal care, health and social services for people of all ages who suffer from a chronic disease or long-lasting disability. These services can be provided in a nursing facility, an adult day care center or at home.

some startling statistics

About 40 percent of all Americans will spend some time during their life in a nursing home. Many more will need home care. Unfortunately, many who require such long-term care may exhaust their financial resources.

Indeed, long-term care can be expensive. For one year of nursing facility care, the national average cost is $20,000-$40,000. Home care can also be costly if services are provided frequently for a long period of time. Just three *unskilled* home health aide visits a week, for one year, can easily cost over $5,000. For three *skilled* home care visits a week, costs can run as high as $10,000 a year.

eligibility

In expanding your benefits package to better meet your needs, HIAA offers its long-term care plan for:

- You (if you are an active employee) and your spouse,
- Retirees and their spouses,
- Surviving spouses of HIAA retirees, and
- Parents (if you are enrolled) and parents-in-law (if you and your spouse are enrolled).

The HIAA Long-Term Care Plan is underwritten by Aetna Life Insurance Company and helps you pay the costs of long-term care.

care providers

Although many people can expect to spend some time in a nursing home, most of us would prefer to be cared for in our own homes, if possible. While many of today's long-term care plans require confinement to a hospital or nursing facility *before* home care benefits are paid, HIAA's Long-Term Care Plan does not. Right from the start you can choose the *type* and *location* of care you prefer—home care, adult day care, hospice care or nursing facility care. Please see the Glossary for definitions of these terms.

Our plan also pays for *informal caregivers*. Since HIAA's plan does not require home care agencies to provide services, a daily benefit will be paid when a *family member or friend* provides custodial care. A daily benefit will also be paid for respite care—temporary short-term, overnight care usually provided in a nursing facility. This coverage allows families to have a brief rest from caring for chronically ill or disabled relatives at home.

enrollment

The open enrollment period is:

For active employees and their spouses	**11/01/89 to 12/15/89**
For retirees and their spouses, and surviving spouses of HIAA retirees	**11/01/89 to 12/15/89**
For parents and parents-in-law	**11/01/89 to 01/31/90**

During open enrollment, you and your spouse may enroll *without having to answer health questions*, provided you are actively at work and your spouse has not been confined to a hospital, nursing care facility or received home health care visits for the 90 days prior to and including the enrollment date.

You are not eligible to enroll if you have a *qualifying loss of functional capacity* on the date coverage would otherwise take effect. See page 12 for a definition of a *qualifying loss of functional capacity.*

In order to enroll your spouse or parents, you must be enrolled in the HIAA Long-Term Care Plan. To enroll parents-in-law, your spouse must be enrolled.

Retirees and their spouses, surviving spouses of retirees, and parents and parents-in-law of active employees will be required to answer health questions and be approved by Aetna before they will be accepted for coverage under HIAA's Long-Term Care Plan. Aetna reserves the right to require a medical exam before approving an individual for coverage.

If you are an active HIAA employee and you want to cover both you and your spouse, you must return the enrollment form to HIAA by December 15, 1989.

If you are a retiree who wants coverage for yourself and your spouse, or if you are the surviving spouse of a retiree and you want coverage, you must return your enrollment form directly to *Aetna* by December 15, 1989.

Parents and parents-in-law who want coverage must return their enrollment forms directly to Aetna by January 31, 1990.

Applications received after these dates will not be accepted. There is no guarantee of future open enrollment periods for active employees and their spouses (no proof of insurability necessary). Also, this may be the only opportunity for parents and retirees to enroll. Future open enrollment periods may be arranged by mutual agreement between HIAA and Aetna.

effective date

HIAA's Long-Term Care Plan will become effective:

- For you and your spouse
  01/01/90
- For retirees and their spouses, surviving spouses of retirees

  The later of 01/01/90, or the first of the month following the month in which the individual's medical information has been reviewed and approved.
- For parents and parents in-law

  The later of 02/01/90, or the first of the month following the month in which the individual's medical information has been reviewed and approved.

your benefit choices

With HIAA's Long-Term Care Plan, you have the flexibility to enroll in a benefit option that accommodates your budget today, without compromising your future needs. You have *three* coverage options which allow you to choose the daily benefit and premium levels that are right for your needs and budget. The low option provides a $60-a-day benefit if you receive long-term care in a qualified nursing facility. The middle option provides $80 per day, and the high option pays you $100 a day. There are several location options—home care, adult day care, and nursing facility care.

If you receive care at home, in an adult day care center, or some other eligible facility other than a nursing facility, you'll receive half the daily nursing facility benefit.

Your Daily Benefit Options

	Low Option	*Middle Option*	*High Option*
Nursing facility	$60	$80	$100
Home care, adult day care, and other eligible facilities	$30	$40	$50
Lifetime maximum	$109,500	$146,000	$182,500

lifetime maximum

Benefits from HIAA's plan are paid up to a lifetime maximum of $18,250 for each $10 unit of benefits purchased for a combination of eligible nursing facility care *or* eligible home care.

For example: If you purchase the middle option, $80-per-day nursing facility benefit/$40-per-day home care or adult day care, your *lifetime maximum* is 8 × $18,250 or $146,000.

- If you receive care exclusively in an eligible nursing facility, you will be eligible to receive $80 per day for five years.
- If you receive care exclusively in an eligible home care unit, you will be eligible to receive $40 per day for 10 years.
- If you receive *both* home care and nursing facility care benefits, you will be eligible to receive payment in any combination up to the lifetime maximum of $146,000, which would last somewhere between five and 10 years.

choosing different benefit options

If you and your spouse enroll in HIAA's Long-Term Care Plan, you both must purchase the **same** option—low, middle or high. The same conditions apply for parents, parents-in-law, retirees and their spouses. However, parents and parents-in-law can purchase coverage equal to, or less than, the coverage you chose when you enrolled.

qualifying loss of functional capacity

To be eligible for HIAA Long-Term Care benefits, you or your covered spouse, retirees and their spouses, surviving spouses of HIAA retirees, parents or parents-in-law must suffer a *qualifying loss of functional capacity* after coverage is effective. This loss must result in the need for continual human assistance in specified activities of daily living. This means that you require ongoing help in at least *two* of the following five activities:

- **Eating:** Doing all major tasks involved in eating.
- **Mobility:** Walking or using a wheelchair any distance on a level surface.
- **Transferring:** Moving between the bed and the chair or the bed and the wheelchair.
- **Dressing:** Putting on and taking off all necessary items of clothing.
- **Toileting:** Getting to and from the toilet, getting on and off the toilet, and performing associated personal hygiene.

A qualifying loss of functional capacity can be caused in two ways:

- By an injury, illness or the effects of aging, which make you physically incapable of performing specific activities of daily living, or
- By a diagnosed irreversible organic mental impairment such as Alzheimer's disease, which makes you incapable of performing the specified activities of daily living.

To determine whether a loss qualifies for the HIAA Long-Term Care benefit, the Aetna case manager evaluates evidence provided by you, your doctor, and other health care providers. **The plan does not pay benefits for any loss of functional capacity that starts within 12 months of the effective date of coverage. If it is caused by a pre-existing condition.** A pre-existing condition is any condition diagnosed or treated within 90 days before long-term care coverage begins. Please refer to the Glossary for the complete definition of pre-existing condition.

where care can be provided

Long-term care may be provided at home by family members and friends, or by trained health care providers, or in an eligible institution.

1. Eligible Nursing Facility—This type of facility is licensed to provide skilled nursing or intermediate care to sick and injured persons on a fee-for-service basis. It must be supervised by a physician or registered nurse and provide full-time, licensed nursing care, seven days a week on the day shift, and it must follow certain operating procedures:
   - It must maintain complete medical records on each patient, and an effective utilization review plan must be in force.
   - The facility is not defined to be a hospital, a home for the aged, or a place mainly for rest, retirement, or for the treatment of alcoholism or drug addiction.
2. Eligible Home Care Unit—A home care unit can be any of the following places where care is received:
   - your home,
   - any other private home,
   - a facility for the retired or aged,
   - an institution which provides residential or continuing care, or
   - an adult day care center.

   A home care unit does not include a hospital, sanitarium, skilled nursing facility or intermediate care facility.

how benefits are paid/waiting period

So that overall plan costs will remain affordable for everyone, there is a waiting period of 90 days after the date of a qualifying loss of functional capacity has been determined by an Aetna case manager before benefits begin. The waiting period helps to hold down costs by eliminating short-term care, which is covered by HIAA's Medical Plan, Medicare, or other health care plans you may have. Throughout the waiting period you continue to make monthly premium contributions.

If you still need care after the waiting period lapses, benefits are paid directly to you if you are an active or retired employee. (Benefits are paid directly to the active or retired employee, even if care is for a covered spouse.) For parents and parents-in-law, payment will be made to you. Benefits may be assigned to a nursing facility.

premium waiver

Premium waiver is an important feature of your HIAA Long-Term Care Plan. It provides added protection should you qualify for long-term care benefits. *After you have satisfied the waiting period and benefits have been paid for 90 consecutive days in any benefit period, you will no longer have to make premium payments.*

Premium payments will continue for any other covered family members, such as spouse, parents or parents-in-law. If, however, you are no longer functionally dependent and long-term care benefits are discontinued one day, premium payments for your own coverage will start again on the first premium due date following that day. If you require long-term care benefits again within 90 days, there is *no additional waiting period.*

What if I need hospitalization after benefit payments begin?

HIAA Long-Term Care Plan benefit payments are suspended while you are in the hospital. Once you return to a long-term care environment, however, while you are still functionally dependent, HIAA benefits will start again without a new waiting period.

portability of coverage

Coverage under the HIAA Long-Term Care Plan is *portable.* This means that if you are no longer eligible as an active or retired HIAA employee, or if the group contract is discontinued, you can continue coverage on a direct-billing basis. Spouses and parents who lose eligibility due to death of, or divorce from, the employee/retiree can also transfer coverage on a portable basis. Any election to continue coverage must be made within 31 days of the date coverage would otherwise end.

To continue coverage, individuals pay the applicable premium plus a monthly billing fee. The monthly fee for 1990 is $2.25 per person. Direct-billed premiums must be paid in advance and are due on the first day of each policy month, with a 31-day grace period. If a premium is not paid within the grace period, long-term care coverage will end.

return of contribution

As an enrolled *active employee*, if you or your enrolled spouse dies while contributing to the plan, all of the contributions made since you enrolled will be returned to your designated beneficiary. Your spouse's contributions will be returned to you. Payment is subject to the following conditions:

- If you or your covered spouse dies while you are making contributions as an active employee, the full amount of your contributions is payable for the person who dies.
- The amount to be returned is decreased immediately, starting at retirement, by 10% *for each year* that you have been retired, or that you or your covered spouse have been making contributions on a portable, direct-billing basis.
- If no contributions are being made at the time of your death—for example, while you are receiving benefits—contributions will *not* be returned.

filing claims

If you believe you are eligible for benefits, you should call Aetna Life Insurance Company within 90 days at **(800) 537-8521** to begin your claim process.

An Aetna case manager, who specializes in long-term care management, will be assigned to handle your claim. The case manager will coordinate and evaluate information about functional incapacity and the projected course of your care for an illness/injury, based on information from your doctor, other health providers, family, and in many cases, an on-site visit. If requested, the case manager will also identify and help coordinate the multiple community-based services that may be needed for your care at home.

NOTE: If a claim is not filed within *one year after the start of a qualifying loss of functional capacity,* benefits may not be paid because of late notice.

extended coverage

This plan has a special feature, which provides extended term insurance coverage for a specified period of time, even if you decide to discontinue your participation in the plan by ceasing contributions. Aetna will calculate and advise you of the period of extended coverage based on your age at the time contributions stop, how long you have been contributing and the interest rates that were in effect while you were a participant. Once your extended coverage is terminated, you no longer can be a plan participant.

when benefits are not payable

The HIAA Long-Term Care Plan **does not pay** benefits for the following:

- **Pre-existing Conditions:** As defined in the Glossary.

- **Government Nursing Facilities:** Care received while confined in a government nursing institution is not covered, unless a charge is made for which you are obligated to pay.
- **War:** Any loss as a result of declared or undeclared war or any act of war.
- **Mental Illness:** A loss caused by mental disease or disorder without demonstrable organic disease (for example, schizophrenia). **Alzheimer's disease is covered.**
- **Self-Inflicted Injuries:** A loss caused by suicide or a suicidal attempt (while sane or insane) or an intentional, self-inflicted injury.
- **Group Policy Duplication:** Any benefits that can be paid under HIAA's Medical Plan, or any other medical plan, for hospital, convalescent, or hospice facility confinements, or home health care in lieu of such confinement.
- **Hospital Confinement:** Any day an insured person is confined in a hospital.
- **Required or Provided Government Benefits:** Any day on which medical benefits for expenses incurred in a nursing care facility, or a home care unit, are provided or required under any law (national or otherwise), other than because of armed forces service or a plan for civilian employees of a government. (For example, benefits provided by Medicare and benefits required by law to be provided under automobile reparations (no-fault) are excluded.)
- **Treatment Outside the U.S.:** A loss or confinement outside the United States.
- **Alcoholism and Drug Abuse:** A loss caused from alcoholism or drug abuse.
- **Workers' Compensation Law:** A loss for which payment is made available through any Workers' Compensation Law.

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costs

It's to your advantage to sign up for the HIAA Long-Term Care Plan at an early age. The younger you are when you enroll, the lower your rates will be. A list of the rates for HIAA's Long-Term Care Plan is included in the pocket of this folder.

The following examples, using the $80 per day benefit for nursing facility care, show the big difference a few years can make in your rate.

- **John** is 32 years old, and his biweekly contribution is **$4.84.**
- **Irene** is 42 years old, and her biweekly contribution is **$8.64.**
- **Rose** is 52 years old, and her biweekly contribution is **$16.36.**

You pay the entire cost of long-term care coverage for yourself and your spouse. The rate you pay over the course of your coverage is based on two factors: the option you choose and your age (and your spouse's age if he or she is enrolled). This amount will be deducted automatically from your paycheck after you enroll. Contributions for retirees, their spouses and surviving spouses will be direct-billed to their home. There will be a $2.25 monthly administrative fee for each person.

Premium contributions for parents and parents-in-law will be **direct-billed to you (the active employee).** There will also be a $2.25 a month, per person administrative fee for direct-billing.

Notice that the age at which you and/or your spouse enrolls is a factor in the cost of long-term care insurance. Once you enroll in the plan, your contributions *do not increase* as you get older. Of course, if long-term care insurance premiums for HIAA are adjusted for **all** plan participants, these adjusted rates will be passed on to you.

Your rate will also change if you *increase* your benefit level. **The cost for the additional coverage will be based on your age at the time of purchase.** Thus, your new premium will include the original rate you paid for the coverage you purchased at an earlier age, *plus* the cost of the additional coverage at your subsequent age.

Remember, regardless of whether you are an active or a retired employee, if both you and your spouse enroll, you must each purchase the same amount of coverage. Premiums are based on your individual ages. Parents and parents-in-law may purchase coverage equal to or less than yours.

determining your entry age

The entry ages for active employees and their spouses are their ages as of the effective date of the plan.

For retirees and spouses, surviving spouses of HIAA retirees, parents and parents-in-law, your entry age is your age as of the first of the month following the date Aetna receives your medical questionnaire.

For those whose application is late, your entry age is your age as of the first of the month following the date that Aetna approves your medical questionnaire.

deciding on how much coverage to purchase

The amount of coverage you choose depends on a variety of factors. Consider your family medical history as well as your overall health. What sources of income do you have and what are your expenses? Are either of these likely to change?

increasing your coverage

You will have *two* different options during *specific time periods* to increase your coverage and help you keep up with the rising cost of home care and nursing facility expenses.

- **Purchasing an additional benefit unit of $10 without supplying proof of insurability**—In calendar years ending in *two* and *seven*, anyone enrolled under the HIAA's Long-Term Care Plan, but not receiving benefits (or within the waiting period), will have the opportunity during the annual enrollment period to purchase one additional benefit unit ($10 nursing facility/$5 home care) without answering medical questions. An additional benefit unit can first be purchased in 1992, again in 1997, then each year thereafter ending in two or seven.

The premium cost of the *additional benefit unit* will be based on your age at the time of the purchase.

- **Purchasing additional coverage with proof of insurability**—In calendar years that *do not end* in two or seven, if you are enrolled but not receiving benefits, you will have the option of purchasing additional coverage by supplying proof of insurability. If all health questions are answered satisfactorily, you may purchase additional coverage up to the plan's current daily benefit maximum option.

The daily benefit maximum option of the plan, which is now $100, will *increase* by one $10 benefit unit in years ending in two and seven. For example, in 1992, the maximum daily benefit for nursing home care will be increased to $110 and in 1997 to $120. Therefore, a new employee who enrolls for coverage in 1997 could choose the following coverage levels: $60, $70, $80, $90, $100, $110, or $120.

Your premium for the **additional coverage** will be based on your age at the time of purchase.

> **NOTE:** Additional benefit units with proof of insurability cannot be added during the nonproof of insurability years (1992, 1997, etc.) The daily benefit option of the HIAA Long-Term Care Plan coverage for you and your spouse must be identical. If you purchase an additional benefit unit of $10 without proof of insurability (in years ending in two and seven), your spouse must also purchase an additional benefit unit. In the same manner, if you purchase additional coverage that requires proof of insurability, your spouse must apply and be accepted for the same coverage. In both cases, you and your spouse must maintain the same level of coverage.

decreasing your coverage

You can decrease your long-term care coverage *at any time.* If an active or retired employee reduces coverage, his or her spouse must also reduce coverage by the same amount. Parents and parents-in-law must also reduce coverage to your level, or less, when you do so.

To remain in the plan, no one may decrease the amount of his or her coverage below the low option of $60.

when coverage is terminated

Your group coverage can be terminated. However, generally your benefits are portable. See "Portability of Coverage" on page 7.

As an **active or retired employee**, your coverage will be terminated when *the earliest of* the following occurs:

- Discontinuance of the group contract.
- Failure to make premium payments when due. (Portability is not available to your spouse if your coverage is terminated for this reason.)
- The date the active employee dies.

Your **spouse's** coverage will be terminated when *the earliest of* the following occurs:

- Termination of the active employee's coverage.
- Termination of dependent coverage under the long-term care policy.
- Failure to make premium payments when due.
- Divorce.
- The date of the spouse's death.

Parents' coverage will terminate when *the earliest of* the following occurs:

- Termination of the active employee's coverage.
- Termination of dependent coverage under the long-term care policy.
- Failure to make premium payments.
- Divorce of the active employee.
- The date of the active employee's death.

questions

If you have questions about the plan, or need help enrolling, call the Aetna Hotline at (800) 537-8521. A representative will be available to assist you.

This brochure describes the HIAA Long-Term Care Plan in general terms. If any conflict arises between this description and the plan document, or if any point in the document is not covered, the terms of the plan document will govern in all cases.

glossary of terms

Activities of daily living:

- Mobility: Walking or using a wheelchair any distance on a level surface;
- Transferring: Moving between the bed and the chair, or the bed and a wheelchair;
- Dressing: Putting on and taking off all necessary items of clothing;
- Toileting: Getting to and from the toilet, getting on and off the toilet, and performing associated personal hygiene; and
- Eating: Doing all major tasks involved in eating.

Acute care: Skilled, medically necessary care provided by medical professionals, with the goal of restoring health or the ability to function.

Adult day care center: An organization that provides a program of adult day care which meets all of the following tests:

- It is operated as an adult day care center in accordance with any applicable laws.
- Its staff includes all of the following:
  - — a full-time director,
  - — one or more registered nurses in attendance during operating hours for at least four hours a day,
  - — enough full-time staff members to maintain a client-to-staff ratio of no higher than 8 to 1,
  - — a dietician,
  - — a licensed physical therapist, and
  - — a licensed speech therapist.
- It operates at least five days a week for a daily minimum of six hours and a maximum of 12 hours.
- It keeps a written record of medical services given to each client.
- It has established procedures for obtaining appropriate aid in the event of a medical emergency.

Benefit period: A period of consecutive days that *begins* on the first day of a qualifying loss of functional capacity. During the first 90 days of that period, no benefits will be paid. If the insured person continues to have a loss of functional capacity, benefits will begin as soon as the 90-day waiting period has been satisfied. A benefit period *ends* with the close of a 90-consecutive-day period during which the insured person has not had a qualifying loss of functional capacity and therefore no benefits have been paid. Once a benefit period has ended, no additional benefits will be paid until the end of the new waiting period.

Confinement: For purposes of an adult day care center, means attendance at an adult day care program. If a retiree or a dependent has been confined due to disease or injury during the 90 days prior to and including the date coverage would otherwise have become effective, that coverage will be deferred until he or she has been free of all confinement at home, in a hospital or elsewhere for 90 days. Confinement at home means that a retiree or dependent must be bedridden or homebound due to disease or injury to an extent that leaving home is medically inadvisable except:

- for brief periods, when accompanied; or
- to seek medical treatment in a hospital or doctor's office.

Custodial care: Care that is primarily for the purpose of meeting personal needs such as help in walking, bathing, dressing, eating or taking medicine. It can be provided by someone without professional medical skills or training.

Doctor: A legally qualified physician.

Eligible home care unit:

- Your home, or any other private home,
- A home for the retired or aged,
- An institution that provides residential care, and
- An adult day care center.

It is **not** a hospital, a sanatorium or a nursing care facility.

Home health care: May include care received at home such as part-time skilled nursing care, speech therapy, physical or occupational therapy, part-time services of home health aides, or help from homemakers or choreworkers.

Hospice care: Nursing care services provided to the terminally ill and counseling for their families. Hospice care can be provided in nursing care facilities or in the patient's home, where nurses and social workers visit the patient regularly.

Hospital: A licensed institution which:

- Mainly provides inpatient diagnostic and therapeutic facilities for surgical and medical diagnosis, treatment and care of injured and sick persons;
- Charges its patients for the services it provides;
- Is supervised by a staff of physicians; and
- Provides registered nurse services 24 hours a day.

It is **not** mainly a nursing home or a place for rest, the aged, drug addicts or alcoholics.

Intermediate care: Occasional nursing and rehabilitative care that can only be performed by, or under the supervision of, skilled medical personnel. This care must be based on a doctor's orders.

Intermediate care facility: One that is licensed by the state and may be certified by Medicaid to provide intermediate care. It may also provide custodial care.

Lifetime maximum benefit: The total maximum benefit payable under the plan during the lifetime of each covered individual.

Medicaid: The joint state and federal program that provides payment for health care services to those with lower incomes or with very high medical bills. It does include benefits for skilled and intermediate nursing home care and home health care, provided the individual meets Medicaid eligibility requirements.

Medical questionnaire: A special evidence-of-insurability form designed for long-term care coverage.

Medicare: The federal program designed to provide those age 65 and over, some disabled persons and those with end-stage renal disease with help in paying for hospital and medical expenses. Very limited benefits for long-term care are provided by Medicare.

Medigap: Medicare supplemental insurance which is private insurance, supplements or fills in many of the gaps in medical coverage. It does not provide coverage for long-term care.

Nursing care facility: A licensed institution, or a distinct part of one, which meets all of the following tests:

- It provides, on an inpatient basis, for persons convalescing from injury or disease:
  - skilled nursing care or intermediate nursing care, rendered by a registered nurse, or by a licensed practical nurse under the direction of an registered nurse; or
  - physical restoration services to assist patients in reaching a degree of body functioning that will permit self-care in essential daily living activities.
- It charges its patients for the services it provides.
- The services are supervised full-time by a doctor or registered nurse.
- It keeps a complete medical record on each patient.
- It has an effective utilization review plan.

It is not mainly a hospital, place for rest, the aged, drug addicts, alcoholics, mentally retarded people, custodial or educational care, or care of mental disorders.

Pre-existing condition: Any condition diagnosed or treated within the 90-day period preceding the effective date of long-term care coverage. Any qualifying loss of functional capacity that begins **within** 12 months after coverage starts and is caused by a pre-existing condition, is not covered. If, however, the qualifying loss of functional capacity begins **after** 12 months of coverage, the pre-existing rules do not apply.

Premium waiver: Suspends maximum payments after an insured person has received benefit payments for 90 days.

Qualifying loss of functional capacity: Determined by the need for continual human assistance in performing at least two of the activities of daily living as determined by Aetna.

Respite care: Temporary short-term overnight care for the sick or disabled, usually provided in a nursing care facility. It allows families to have a brief rest from caring for chronically ill or disabled relatives at home.

Skilled nursing care: Daily nursing and rehabilitative care that can be performed only by, or under the supervision of, skilled medical personnel. This care must be based on a doctor's orders.

Skilled nursing care facility: One that is licensed by the state and may be certified by Medicare and/or Medicaid to provide skilled nursing care. It may also provide intermediate or custodial care.

Waiting period: A period of 90 days during which no benefits will be paid. This waiting period starts on the date that Aetna determines a qualifying loss of functional capacity has begun.

The Association reserves the right to revise at any time any of the benefit plans it offers to employees.

Item 2

T.H.E. RESPITE Alternative Adult Care Program
P.O. Box 294 Mechanicsville, PA 18934 (215) 794-3278

November 2, 1989

Honorable John H. Heinz, III
9456 Federal Building
600 Arch Street
Philadelphia, PA 19106

Dear Senator Heinz:

Skip Irvine, of your office, has asked me to submit the enclosed testimony on behalf of Adult Day Care for the Pepper Commission.

It is an honor to be able to represent the disabled, frail and at risk older population. Thank you for allowing me to participate in these hearings.

Sincerely,

Nancy G. Tatem, RN, C, BSN
Administrator

History of T.H.E. Respite

My partner, Phyllis Eckelmeyer, and I embarked on a career in Adult Day Care (ADC) in January of 1986. It was new to both of us, has changed our lives, reaffirmed our values and given us insight into the dynamics of aging in America.

A year of combined effort and hard work preceded our opening. All of the research, permits, surveys, paperwork, acquisitions, conferences and doubts that precede any business endeavor occurred. The most difficult obstacle, however, was finding a location. Facilities are most often leased and located on the premises of a religious, nonprofit or community service organization, such as a YMCA or church. Few of this select group conform to three primary requirements: handicap accessible space conforming to licensure regulations; reasonable rent; and a desire to allow an ADC to operate on the premises. Beyond this, there must be handicap toilet facilities, access to transportation and means of meal preparation or delivery.

At the end of our first year, we had served a total of eight clients. My partner and I did everything, with the help of our families, for 20 months before we could afford to hire part-time employees. During this time, our census climbed to six full-time and six part-time clients.

From its inception, we projected that finances would be difficult. To meet expenses, we have run special event fund raisers every four months, such as craft bazaars and rummage sales. We receive donations from local charitable organizations, businesses and individuals. We also have a memorial fund to which people can contribute. Without these, we would be unable to stay in business. Unfortunately, they divert much of our energy from our main purpose of providing care to our clients, which now numbers 20, an average of 10 clients daily.

Some of the duties we perform, as the only administrative staff, on an ongoing basis include: program planning and coordination, plan and run fund raisers, attend educational and informational courses, give direct client care, provide meals, shop and inventory, administrative duties, marketing and advertising, formulate business plans, write proposals, carry out mandates of board of directors, facilitate support groups and speak to community organizations, network with community and social service agencies, follow up on potential client inquiries, gather statistics for government and private surveys on ADC, counsel client families, make referrals to community agencies, monitor client's health and progress, make recommendations based on our observations, update health care providers on client's progress, hold family conferences, in-service staff, conduct staff meetings, general cleaning and capital improvements.

Estimates project that one out of three ADC's fail in the first year. This is not surprising.

Problems of ADC

The past decade has seen a movement away from institutionalization. The grass roots effort to provide care to the fixed limited income disabled and elderly is hard pressed to provide quality programs for a reasonable fee. Concurrently, federal funding programs have been cut drastically. The elderly in need of assistance must seek nursing home care where Medicaid picks up the bill, even if they would prefer to remain with family or in their own homes. At this time, there are no third party payers for adult day care and little funding for clients.

President Bush has called for a renewed volunteer effort. Many of those who would traditionally be willing to volunteer have continued or returned to work. Approximately one-third of our female caregivers must work to pay for day care.

Our Area Agency on Aging (AAA) has been very supportive of families trying to keep loved ones at home. Approaches have been creative in providing combinations of funding, homemaker services, meals on wheels, counseling, as well as vouchers to redeem for hard goods (adult diapers, supplemental feedings, etc.). Their funds are also limited. Of the five AAA funded slots vacated at T.H.E. Respite this year, none has been refilled. The funding which one year ago was divided among five ADC's in our county must now be divided among eight.

The most pressing and heartbreaking need is seen in those clients who do not qualify for funding from any source. Some are over 65 couples where the husband has a small pension or income in addition to Social Security, which disqualifies both from care. When the husband dies, the wife loses a mate, his pension and a good portion of Social Security, but has no one to negotiate the health care maze now that she is eligible for funding which she may not get, depending on the variables. Some clients have come from other countries to live with family and haven't resided in the U.S.A. long enough to receive any benefits. Those disabled and under 65 are in a vulnerable situation. Some limp along on Social Security or SSI and may qualify for subsidized housing, but have no money left for day care. There is no source of funding for these clients. These groups are denied the peer socialization, nutritional supports and health monitoring ADC offers.

We have sought scholarships from community organizations, churches and businesses without success. Profiles or case histories maintaining anonymity similar to "adopt a child" format have been offered, also unsuccessfully.

Insurance policies and government funding programs must be extended to cover ADC as a long term care option. Local funding should be improved to allow agencies to develop a broader sliding scale covering those whose finances are marginal at this point. This would permit increased numbers of clients to utilize a very cost effective and dynamic service. It would perhaps place ADC's on a less stringent financial base and allow them to create some type of sliding scale of their own.

Business and industry would be wise to consider offering ADC on a menu of benefits to its employees. Knowing that their elderly loved ones are cared for would decrease tardiness and absenteeism among caregiving families and ensure their peace of mind while away from home. Additionally, federal tax deductions should be allowed for caregivers utilizing ADC in order to keep clients at home and so that they may continue their lives.

The psychosocial model of ADC (as opposed to medical model) should remain a community based service. Those who require medical care, such as peritoneal dialysis, perenteral nutrition, tube feedings and ventilator support, require skilled and technical care. A medical model day care is more appropriate for this patient. Conversely, the client who does not qualify for this type of care should not be in an environment which delivers it.

Kinds of Service Offered by ADC

T.H.E. Respite, as other Pennsylvania ADC's, provides a variety of services. We have a regular program which features daily current events (our brand of reality orientation) with historical comments, exercise modified for our population and done in chairs, crafts, art, intergenerational activities with preschoolers through high school age, music, dance, pets, plant care, entertainers, speakers, health care tips and monitoring, a podiatrist and hairdressing. We perform any personal care our situation permits, such as nail and skin care, incontinance care and shaving. We are currently involved in writing grant proposals in an effort to expand service to include showers or a whirlpool to respond to a need identified by our caregivers. Some ADC's have been doing this successfully.

Staffing for us has not been a problem, as in other long term care situations. We have consistently attracted an extremely well qualified caring staff, such as teachers, nurses, social workers, those with art, craft and music backgrounds and college students. Exit interviews provide us with the information that 90% of those leaving do so citing the need for full-time, better paying positions. We lose good people because we can't compete in the wage category.

Feedback

Positive quotes from our caregivers are endless. "I couldn't keep mother at home if it weren't for day care." "We are so glad 'John' has something to do during the day that brightens up his life." "My mother cared for me and I want to care for her. I don't want her to end her life with strangers." This client passed away at home two weeks ago, six weeks after her last day at T.H.E. Respite. "I want my wife to come five days a week so she doesn't miss anything." This lady died at home, watching T.V. with her husband, two weeks after leaving T.H.E. Respite for the last time. Friends and strangers, on learning what we do, say "If you had only been here for my father." "What you do is so needed." "I have a friend who has her mother with her and . . . . "

Our caregiving families are a huge source of support. They assist with our fund raisers and other activities. Many designate us for memorial gifts or other sources of giving. Many attend our support groups even after their loved one has left T.H.E. Respite. Some have made donations of craft supplies, food and invalid items, such as wheelchairs, showerchairs and commodes. The son-in-law of one of our former clients has written several grant proposals for us on his own time, gratis. His wife is a very active and valuable member of our board of directors.

Why ADC is Important

ADC gives clients and their caregivers options and opportunities. It is a service designed to expand with the ever increasing older population with growing needs for appropriate cost effective care. ADC allows caregivers to continue or resume their life-style and gives them a respite from caregiving responsibilities. Caregivers, sandwiched between the needs of aging parents and those of spouse and children, affirm the benefits of allowing ADC to share their burden. For many, ADC is the only long term care option they will consider. Others find that it eases the transition from home to another type of long term care. All who wish to keep family members at home and in the community, find they are better able to render the type of loving care the person deserves, economically, with reduced stress and comfortable in the knowledge that their loved one is cared for just as they would do themselves.

The ratio of staff to client in ADC generally falls between 1:3 and 1:5. Identifying individual needs and developing programs to meet those needs is much easier than when ratios are higher or the focus of care is different.

Daily care at T.H.E. Respite is $30, as opposed to $45 - $115 per day for other long term options.

Clients are carefully screened prior to admission to insure that we are mutually suited to one another. Caregivers and clients benefit from discharge policies that clearly set forth the scope and limitations of ADC. We work closely with families, caregivers and community resources to insure that the client who must move on is placed in an agreeable and comfortable situation.

ADC is a viable, caring, low cost community service. It allows families to remain intact and people to stay in their homes longer by providing protective and stimulating daily care by qualified individuals who recognize the client's needs and limitations. ADC is capable of growing with the demands of the escalating older population while continuing to offer individual attention to the impaired, at risk, frail and elderly.

Item 3

November 3, 1989

Senator John Heinz
% Pepper Commission
9456 Federal Building
600 Arch Street
Philadelphia, PA. 19106

Dear Senator Heinz:

The Philadelphia Mental Health Aging Advocacy Committee, a coalition composed of administrators, practitioners and consumers committed to the cause of quality long term comprehensive care for the elderly appreciates this opportunity to express our concerns regarding the needs of a population which has been undeserved and overlooked. Federal policy in recent years has been to accelerate the deinstitutionalization of the mentally ill from State mental hospitals.

Many of the mentally ill have been transferred to nursing facilities or boarding homes. A comprehensive survey conducted by the National Center for Health Statistics in 1977, estimated that 750,000 (60%) of the nation's 1,300,000 nursing home residents have a primary or secondary mental health diagnosis. Obtaining a precise count of the number of nursing home residents with mental disorders is difficult because of the limited expertise available in nursing homes to make sophisticated diagnoses. The diagnostic situation is compounded by the multiple inter-reactive process of physical and mental illness which is particularly characteristic of the aged. (Psychiatry Update, The American Psychiatric Association Annual Review, Vol. II, 1984.)

There are 694 nursing facilities in the State of Pennsylvania which can accommodate 87,713 residents. Philadelphia is a city which has a 20% representation of people 60 years of age or older in their total population. For this reason the 57 nursing homes in Philadelphia which house 9,020 people do not currently meet the demand for placement. The Delaware Valley Hospital Council (DVHC) reports a shortage of 2,800 nursing home beds in the Southeastern Pennsylvania Region which includes Philadelphia. According to the DVHC, the need of additional beds is particularly striking in Philadelphia with 80% of the beds required for Medicaid patients.

Due to Medicaid's inadequate reimbursement structure, the DVHC points out that the number of Medicaid-certified beds " does not meet the needs of the Medicaid eligible population." Combined Census Bureau and Pennsylvania Department of Aging data suggest that the need for long-term care residential care services will increase by 42% in the Southeastern Region of Pennsylvania between 1990 and the year 2,000. (Community Services Planning Council of Southeastern Pennsylvania, An Aging Agenda, The Unresolved Issues of Long Term Care, 1987)

Two major barriers to nursing home placement are (1) eligibility for publicly funded long term care (Medicaid) upon admission; (2) a history of current illness or psychiatric diagnosis. Discrimination against admission of Medicaid patients by nursing homes is a widespread practice. In Pennsylvania, a combination of federal and state Medicaid cost cutting measures has resulted in a preference for private pay patients and a corresponding lack of access to nursing home beds for those who are eligible for Medicaid admission. (Philadelphia Health Management Corporation, Long Term Care for Special Populations, 1987).

There are no on-going treatment programs for mentally ill nursing facility residents in Pennsylvania (Persky, A Report On The Lack of Mental Health Services in Nursing Homes, 1987). Medicaid and Medicare will reimburse (at a low rate) for the services of a psychiatrist in a nursing home. Only a limited number of psychiatrists are available for nursing home visits. Other mental health professionals are not entitled to reimbursement from public or private sources.

Although the quality of care in nursing homes is expected to improve as a result of the OBRA legislation, there is a significant gap in the quantity of nursing home beds. Pennsylvania is in the fifth year of a state-imposed moratorium on nursing home bed construction under the Medical Assistance Program. Institutional alternatives are becoming scarcer as the rate of growth of the elderly population requiring these services exceeds that of all other age groups (An Aging Agenda, Community Services Planning Council of Southeastern Pennsylvania, 1987).

The limited capacity of nursing homes to deal with the mental health problems of residents has been noted in various reports (DHHs, 1980; GAO,1982: Talbott, 1985). Studies of mental health care in nursing homes emphasize that the intent of these settings is the care of the aged and infirm, not the mentally ill (Carling, 1981). Nursing home staffs are seldom qualified to deliver mental health care (GAO,1982) and may show negative attitudes toward mentally ill residents.

A parallel problem exists in Pennsylvania's Personal Care Facilities, where residents with mental health and/or medical needs lack the provision of adequate health and social services (Personal Care Home Task Force Preliminary Report, 1987). Data collected for a 1988 report by the Conservation Company of Philadelphia identified 26,000 Pennsylvanians residing in 1,350 licensed personal care boarding homes--the capacity of these homes ranges from 4 to 350 beds.

Characteristics of boarding home residents were noted as:

18%--severely restricted in physical mobility

17-25%--serious impairment of mental functioning

5%-marked inability to perform Activities of Daily Living

10-13%--poor or unstable health status

25%-lacking regular, preventative health care

8-12%-exceptionally isolated or depressed

89%--over the age of 60

The Conservation Company Study reported that "the Southeastern Region of Pennsylvania has a considerably greater number of persons at risk because they lack regular supports in the community and because they do not receive consistent health care services". Limited preventative care was most often found in the mid and large size homes. A 1972 survey conducted by Temple University Center for Social Policy and Community Development found that 45% of the Philadelphia boarding home residents were mentally handicapped, 5% were physically disabled, and 20% had multiple handicaps.

In 1987, the Philadelphia Mental Health Care Connection, a subsidiary of the County Office of Mental Health and Mental Retardation instituted a program of Intensive Case Managers assigned to specific board and care homes. Currently, there are seven managers who are responsible for tracking and linking residents to mental health and other services. An important component of the program is the training provided to boarding home operators aimed at increasing their knowledge and skills in dealing with individuals with mental health problems. Over the next two years six additional managers will be recruited to serve 390 residents in 13 homes. The designated population for intensive case management services are medicaid eligible boarding home residents who have been diagnosed as severely and persistently mentally ill. Pennsylvania has been granted a HCFA waiver enabling these services to be reimbursed by Medicaid.

Boarding home operators express their dissatisfaction with existing SSI reimbursement rates which lag behind increased inflationary costs. Another source of frustration is the burden of additional regulations, which in the opinion of many operators, do not contribute to improved care.

All evidence suggests that board and care will continue its rapid growth into the future. Mental health care and nursing home care costs are likely to increase well above the national inflation rate. Board and care offers the potential for a positive alternative to institutional care available to elderly, disabled Americans. However, the conclusions in the Report of the SUBCOMMITTEE ON HEALTH AND LONG-TERM CARE of the SELECT COMMITTEE ON AGING HOUSE OF REPRESENTATIVES, 1989 stress the critical need "of regulation, accountability, and compassion by the Federal Government and the States" to insure that this programmatic element conforms to standards consistent with a coordinated comprehensive health care system.

It is apparent, from this brief review, that most residents of nursing facilities and board and care homes are not receiving adequate mental health care. While Federal policy has encouraged the reduction of state hospital populations, existing reimbursement mechanisms and service structures have restricted the provision of appropriate services for persons requiring long term mental health care. Federal policy rationale for the lack of reimbursement is that the care of the mentally ill has been and still is a state responsibility.

For the population with long term mental health problems who may also have physical problems, the expectation that they can independently seek help from a community mental health center is not realistic. This group requires outreach, case management, and in-home care which is more costly then the on-site services available from a community mental health center.

Current policy and practices have resulted in significant numbers of the mentally ill being trapped in a cycle of hopeless chronicity. While people of all ages are affected by the existing service gaps, the impact on those 60 years of age or older is particularly striking. The relationship of poverty and physical illness characteristic of this cohort to mental illness has been consistently documented in the professional literature (Shane, Weeden, and Lurie, 1982, GAO Report, In addition to their physical problems, the elderly are more likely to have life situations such as reduced income, loss of social roles, stigma of ageism, loss of relatives or friends all of which impact on their psychological well being. It is estimated that 18 to 25% of the elderly experience mental health problems ranging from mild depression to acute psychosis. The existing service system is not responsive to the diversity of health and psycho-social needs presented by the elderly and the inter-dependence of their physical and mental health problems. Current funding patterns do not encourage or reward collaborative efforts by human service systems.

Many people with long standing disorders may not be cured but with assistance can be maintained with a greater degree of dignity then has been demonstrated in the past.

We commend you and your staff for the interest you have shown in developing a Federal long term care policy. Mental health is so inextricably linked to physical well being that it should be considered an essential element of extended programs for people of all ages. If, in the course of your committee work, additional information concerning long term mental health care is needed, we would be glad to respond to your request.

Sincerely,
Trudy Persky
Trudy Persky, Facilitator
Philadelphia Mental Health Aging
Advocacy Committee
520 N. Delaware, 4th Floor
Philadelphia, PA. 19123
Telephone: 215-923-0400

Item 4

NEW JERSEY RETIRED
EDUCATORS ASSOCIATION
180 W. State St., P.O. Box 1211, Trenton, New Jersey 08607-1211, (609) 599-4561

STATEMENT BY FRANCES DUTHIE, REPRESENTING THE NEW JERSEY RETIRED EDUCATORS ASSOCIATION BEFORE THE UNITED STATES BIPARTISAN COMMISSION ON COMPREHENSIVE HEALTH CARE ON NOVEMBER 13, 1989

WE ARE AWARE OF THE GREAT RESPONSIBILITY OF YOUR COMMISSION TO MAKE RECOMMENDATIONS TO CONGRESS REGARDING FEDERAL LONG TERM CARE SERVICES FOR THE ELDERLY AND DISABLED AND COMPREHENSIVE HEALTH CARE SERVICES FOR ALL INDIVIDUALS IN THE UNITED STATES.

THE MAJOR HEALTH NEED OF THE NEW JERSEY RETIRED EDUCATOR IS A PROGRAM FOR LONG TERM HEALTH CARE IN THE HOME, COMMUNITY, OR NURSING HOME. MANY LIVE IN FEAR THAT IF THEIR HEALTH NEEDS GO IN THIS DIRECTION, THEY WILL BE REDUCED TO ABJECT POVERTY. THIS HAS HAPPENED TO SOME OF US.

ALTHOUGH THIS IS A NATIONAL PROBLEM, IT IS PARTICULARLY ACUTE IN NEW JERSEY, SINCE WE HAVE MANY SENIORS. NEW JERSEY HAS THE SECOND HIGHEST MEDIAN AGE OF 34.5 YEARS. BY THE YEAR 2000, 1.2 MILLION OF THE STATE POPULATION ARE PROJECTED TO BE OVER 65 YEARS. RESEARCH ESTIMATES OF 1986 PLACE 625,000 NEW JERSEY CITIZENS UNDER AN ANNUAL INCOME OF $28,699. WITH ANNUAL NURSING HOME COSTS AT ABOUT $25,000, IT IS OBVIOUS THAT VIRTUALLY EVERY ONE OF THE 625,000 SENIORS WOULD HAVE DIFFICULTY PAYING FOR ANNUAL NURSING HOME FEES. TWENTY-FOUR THOUSAND OF THIS NUMBER HAVE AN INCOME BELOW $7,200. THESE PERSONS WOULD NORMALLY QUALIFY FOR MEDICAID. THE REMAINDER WOULD EXIST IN A SEA OF DOUBT WITH EVERYTHING THEY OWN AT RISK. THOUSANDS OF THE 334,148 SENIORS WHOSE ANNUAL INCOMES ARE ABOVE $28,700 WOULD ALSO BE AT RISK IN CASE OF A CATASTROPHIC ILLNESS. THE ATTACHED TABLES 1 AND 1A ILLUSTRATE THE FINANCIAL CONDITION OF NEW JERSEY'S SENIOR POPULATION IN 1985.

OTHER FORMS OF LENGTHY CUSTODIAL HEALTH CARE ALSO TAX THE FINANCIAL MEANS OF SENIORS SUCH AS HOME CARE, DAY CARE, REHABILITATION INSTITUTIONS, CERTAIN FORMS OF FAMILY CARE, AND SO FORTH.

A PERENNIAL PROBLEM WITH MOST HEALTH CARE SYSTEMS IS THAT THEIR COMPLICATIONS ARE DIFFICULT FOR MANY USERS TO UNDERSTAND. SPECIFIC STEPS SHOULD BE TAKEN TO EDUCATE NOT ONLY USERS BUT ALL CITIZENS RE ANY HEALTH PLAN DEVISED ON ANY LEVEL.

AS WE AWAIT YOUR REPORT WE LOOK FOR ALTERNATIVES.

OUR ASSOCIATION IS STRONGLY SUPPORTIVE OF A FEDERAL, SOCIAL INSURANCE APPROACH TO LONG TERM CARE FINANCING. WE WILL CONTINUE TO SUPPORT THIS APPROACH AS BEING IN THE BEST INTEREST OF OUR MEMBERS AND THE PUBLIC.

AS AN INTERIM STEP WE ARE SUPPORTING THE DEVELOPMENT OF A PUBLIC/PRIVATE COOPERATIVE EFFORT IN OUR STATE. WE HAVE BEEN WORKING WITH STAFF IN THE STATE GOVERNMENT FOR OVER A YEAR IN THE DESIGN OF A PROGRAM THAT WILL MEET THE UNFILLED NEED IN OUR STATE FOR AFFORDABLE LONG TERM CARE COVERAGE. THIS PROGRAM WILL BRING LONG TERM CARE COVERAGE TO LOWER AND MIDDLE INCOME ELDERLY WHO WOULD OTHERWISE SPEND DOWN THEIR LIFE SAVINGS WHEN FACED WITH LONG TERM CARE. WE ARE ESPECIALLY ENCOURAGED BECAUSE THIS PROGRAM WILL ADDRESS QUALITY AND AVAILABILITY OF SERVICES THROUGH A MANAGED CARE COMPONENT. THE PROGRAM IS EXPECTED TO REDUCE COSTS BY ELIMINATING MARKETING AND SALES COMMISSIONS AND ENHANCE BENEFITS THROUGH CERTAIN MEDICAID WAIVERS.

THE NEW JERSEY DEMONSTRATION IS INTENDED TO BE A PILOT APPROACH LIMITED TO A SPECIFIC GROUP OF PEOPLE. WE ARE ENCOURAGED THAT THE RESULTS OF THIS DEMONSTRATION PROGRAM WILL CONTRIBUTE TO THE TECHNICAL KNOWLEDGE THAT WILL MAKE A NATIONAL PROGRAM WORKABLE AND PREVENT A REOCCURRENCE OF THE PROBLEMS WE ENCOUNTERED WITH MEDICARE CATASTROPHIC. WE ARE EXPLORING THE POSSIBILITY OF OFFERING THIS PILOT PROGRAM TO OUR MEMBERS AS A MEANS OF ADDRESSING THEIR NEEDS UNTIL A NATIONAL SOLUTION IS IMPLEMENTED.

IN THE MEANTIME WE URGE YOUR COMMISSION TO LEAVE NO STONE UNTURNED TO PROVIDE A SYSTEM OF COMPREHENSIVE QUALITY HEALTH CARE TO EVERY AMERICAN CITIZEN.

TABLE 1

NUMBER OF ELDERLY PERSONS IN NEW JERSEY BY AGE, SEX AND INCOME, 1985

		Family Income				
	Total	<$7,200	$7,200-$12,399	$12,400-$17,799	$17,800-$28,699	$28,700+
65-74						
Males	253,000	8,588	29,832	38,366	53,185	123,030
Females	331,000	35,271	61,022	50,773	62,184	121,750
Total	584,000	43,859	90,855	89,139	115,368	244,779
75-84						
Males	104,000	9,104	17,449	15,295	26,891	35,261
Females	183,000	38,653	48,807	27,185	31,272	37,083
Total	287,000	47,757	66,256	42,480	58,163	72,344
85+						
Males	24,000	3,125	5,005	4,423	3,264	8,183
Females	63,000	21,724	14,201	11,822	6,411	8,842
Total	87,000	24,849	19,207	16,245	9,675	17,025

SOURCE: Lewin/ICF estimates using a 1983-1986 pooled March Current Population Survey, Center for Health Statistics, New Jersey Department of Health estimates, and the Brookings/ICF Long Term Care Financing Model.

TABLE 1A

NUMBER OF ELDERLY PERSONS IN NEW JERSEY BY AGE, SEX, AND INCOME, 1985, Row Percentages

		Family Income				
	Total	<$7,200	$7,200-$12,399	$12,400-$17,799	$17,800-$28,699	$28,700+
65-74						
Males	100.0%	3.4%	11.8%	15.2%	21.0%	48.6%
Females	100.0%	10.7%	18.4%	15.3%	18.8%	36.8%
Total	100.0%	7.5%	15.6%	15.3%	19.8%	41.9%
75-84						
Males	100.0%	8.8%	16.8%	14.7%	25.9%	33.9%
Females	100.0%	21.1%	26.7%	14.9%	17.1%	20.3%
Total	100.0%	16.6%	23.1%	14.8%	20.3%	25.2%
85+						
Males	100.0%	13.0%	20.9%	18.4%	13.6%	34.1%
Females	100.0%	34.5%	22.5%	18.8%	10.2%	14.0%
Total	100.0%	28.6%	22.1%	18.7%	11.1%	19.6%

SOURCE: Lewin/ICF estimates using a 1983-1986 pooled March Current Population Survey, Center for Health Statistics, New Jersey Department of Health estimates, and the Brookings/ICF Long Term Care Financing Model.

Item 5

CAPS

CHILDREN OF AGING PARENTS

TESTIMONY ON NOVEMBER 13, 1989

TO: Pepper Commission

FROM: Mirca Liberti

The need for adequate long-term care for the infirm elderly has always been a concern of our orgznization. Long-term care in the home prevents premature institutionalization. Many families who care for an infirm elderly person look for home care health services to aleviate the stress on the primary caregiver and to provide the elderly inform with a skilled level of care.

Although there are many agencies offering some form of home health care, such as health aides, companions and homemaker services, these do not either give enough hours of coverage or reach out to service those in the community who do not meet the stringent medical requirements and/or the financial requirements. These people are left out of the existing delivery system for home health services. While there are several efforts that are being made to provide volunteer respite care and paid attendant care, the present budget cuts effect these services so that we feel that the home base services are not meeting the existing needs of the infirm elderly in the community. There is virtually no insurance which covers home care services on a long term basis. We look to our elected officials to include in the Human Services budget the above mentioned services with less rigid requirements and expanded benefits so that the services can reach out to more people.

As a caregiver, I spent approximately $50,000 over a period of seven years for home care and medical expenses, not reimbursed by medical insurance, for my father so that I could continue working. This care ranged in cost from between $5.00 to $6.00 per hour for eight hours a day. Somewhere between $200 to $300 was spent for the services that I felt were needed to keep my father adequately cared for in my home.

It is not right to expect a family to impoverish itself to provide the help for an elderly parent who may or may not have enough financial resources to buy home health care services. The very rich can afford services, the very poor can meet the requirements to get services through the social service agencies. It is the middle group that is being squeezed out, being told "you are too rich to be poor and too poor to be rich."

Preventing premature institutionalization or never having to institutionalize saves the community tax dollare, approximately $25,000 yearly, and allows the infirm to live in dignity in his or her own home or with the faily. Adequate home health care and respite care allows the families to care for their elderly without destroying the families through the stresses and strains that long-term care imposes on a family's emotional, physical and financial resources.

EXCERPTS FROM LETTERS RECEIVED

I am currently caring for my 72 year old father in my home. His temper is violent and at times abusive towards my children and myself. He is suffering memory loss. Financially we cannot afford a facility for my father and I am the only living relative he has. I need guidance as this stress is severely damaging my marriage.

Thank you for starting a support group for all of us out here who face, or have faced, the same problems that all of you faced. God Bless! When I was forced to put my 88-year-old mother (who is now 92) in a nursing home several years ago, I thought my guilt would kill me - it almost killed my job and my marriage. Thanks again for shining a ray of hope into the darkness so many of us find ourselves in. Thank you for caring.

My own health has been very poor for years. I suffered a brain aneurysum when I was 17 that left my one leg and arm paralysed. When I was 35 they diagnosed me as having Hodkins Disease which resulted in 9 years of chemotherapy. Having had around 20 operations, my life has not been an easy one. Now for the last 8 months my father has been very ill. My mother has him at home and I am doing all I can to help but it is really dragging me down.. My doctor says that all the stress could cause my cancer to flare up again. My mother says that they took care of me when I was sick so now its my "duty" to take care of them.

Trying to keep up my own apartment plus handling all my folks bills and their problems makes me wonder why I even keep on trying - is life even worth it! I've had to give up all my hobbies and friends as I just don't have the time or energy.

I have for the past year and a half been taking care of my father in his home with no outside financial help. He is completely crippled (only limited use of his right arm) from bilateral strokes suffered a year and a half ago. He requires sitters 24 hours a day to bathe, dress, shave, feed, give him medications and to transfer him from bed to wheel chair and to also transfer when necessary to bedside toilet, etc. This costs us $22,000.00, (not counting living expenses), which was paid by cashing in Life Insurance policies. We have no moneyleft and he may be loosing his home. We don't want to see him go into a nursing home, but the courts are right now threatening to have his house sold and the courts assign him to a nursing home of their choice. How can all this happen in our country?

My grandmother is 90 years old. She is cared for by my four aunts who are on a rotating schedule. They must stay overnight when their turn comes. Also living in my grandmother's home is my physically handicapped uncle and another mentally handicapped uncle.

My aunts who visibly appeared stressed out and physically an emotionally drained break my heart. I believe this situation has put quite a strain on my aunts as well as their own immediate families. I truly believe this is a national problem that needs more attention.

I'm not sure I believe in miracles till I saw your organization listed.

I take care of my dad who is a double amputee, has diabetes, Vascular disease and hardening of the arteries among other things. He is totally dependent upon me. No one tells you where to go, what's out there for help or what kind of information is available for Support Groups and Nursing Homes.

Excerpts

We are trying to care for an elderly (85) year old parent athome. Her income is only $20.00 above the CAP in the State of Texas for eligibility for financial assistance should she have to enter a nursing home. My husband is the sole surviving child, is retired for health reasons and our financial resources do not allow us to help in that area.

On Mom's doctors orders, I have a choice to either quit my job and stay home with her 24 hours or place her in a nursing home. I chose to stay home, She's been with me for 17 years but its only the past 9 years that its become a problem.

She has congestive heart failure, wears a pacemaker and has been hospitalized off and on for the past 6 years with the heart problem and /or pneumonia. Her vision is 20/400 in one eye and sees light only in the other so she's considered legally blind. She's extremely senile and cannot remember what was said by the time you take your next breath.

I haven't worked in 4 years now so I've no income and as I've always supported myself, I find it extremely difficult to have toget by living on her social security check each month. It's not enough to pay the monthly bills yet alone purchase food. Besides I feel like "freeloading" on her monthly check but I've no other choice as I've no savings nor does she.

A county aid has been very unreliabel in the past. There was a period of 8 weeks when she didn't show up at all. The agency she works out of has a contract with the local hospital thru the program and I'd be told repeatedly that they didn't have anyone else to replace her as they are so short of help.

I placed Mom in a nursing home for 6 days as I was expecting a pen pal to visit from Europe for a couple of days. Well that was the one and only time I'll ever put her in a nursing home. Her

Excerpts

medication was withheld on several occasions and one medication was given incorrectly. It was to be given with food or mild but was given with water. Several items of clothes are missinhg. She was treated harshly. On the 2nd day there, I visited her, the head nurse wanted her to lay down so the "house doctor' could examine her. As Mom wasn't laying down fast enough for her the nurse pushed her head down hard making Mom yell out in pain. What had happened? The zipper on her dress had gotten caught in the skin of her neck taking out a piece of flesh. Three days in a row my Mom didn't have any underpants on nor a diaper and her slippers and socks were soaking wet with urine. I had to wash and clean her even though it was their responsibility to see to this. The pay off (and by the way the day I took her out of there, the 6th day) was when I saw a nurse hitting a female patient with a soaking wet bath towel. She was smacking her all over the body. I later found out that this is how they discipline them as it leaves no black and blue marks. Should a black and blue mark develop they must report to the State as to how it happened.

My mother has been house bound for 5 years. This last year she has been in and out of the hospital. We all live together (4 sons, 1 husband, 1 mother and me). I have a full time job, would come home and have to take care of my mother. She can not walk or do anything for herself. I must change her diaper and Colostomy bag. She will not eat unless I'm home. Her friends will not come to see her any longer because she upsets them so much.

My mother's physical problems include angina, back trouble, circulation problems, arthritis, plus side affects from medications she takes for these things and for depression. She has had mental breakdowns regularly for more than 35 years.

In order to care for her I cannot have a life of my own. When ever I go out socially, which is now very rarely, she has a breakdown. Her mental breakdowns have caused me to quit jobs and school at various times.

Item 6

STATEMENT
OF
LAURENCE F. LANE
VICE PRESIDENT FOR REGULATORY AFFAIRS
NOVACARE, INC.

Mr. Chairman:

I am Laurence F. Lane, Vice President for Regulatory Affairs, NovaCare, Inc. NovaCare is the leading contract rehabilitation services corporation in the nation, supplying speech, occupational and physical therapy services to over 2,000 nursing homes, hospitals and home care providers. In twelve jurisdictions, NovaCare operates certified Medicare rehabilitation agencies and outpatient clinics. The company operates in 30 states and the District of Columbia. Our corporate headquarters is located in Valley Forge, Pennsylvania.

Since the advent of hospital prospective payment systems based on diagnostic related groupings (DRG's), patients in need of lengthy rehabilitative interventions are less attractive financially to the acute hospitals. At the same time, both the need and demand for rehabilitation services has mushroomed fueled by greater longevity and the aging of the total population, heightened risk of chronic disability and the application of medical technology to compensate for such limitations. Analysts forecast that between 4.8 and 9.6 million people in the United States today who could benefit from rehabilitation services are not receiving services.

This dynamics offers a challenge long term care resources to develop rehabilitation services.

I understand the Commission has received extensive testimony on developing our home based long term care delivery system, therefore, I will limit my remarks to how we can transform our existing nursing facility capacity to (i) improve the level of rehabilitative caring within nursing homes, (ii) enhance patient access to SNF based rehabilitation services, and (iii) achieve cost effective service. I will suggest a program of legislative improvements which would significantly enhance the provision of rehabilitation services in the nursing home setting.

I. Compatibility of SNFs and Medical Rehabilitation:

Comprehensive medical rehabilitation is the provision of interdisciplinary teams of therapists, physicians, nurses and social workers focused on the patient's restoration of lost functional capacity and the elimination of disability. The goal is to improve patient's functioning at a higher level of independence. Elimination of a disability could be achieved by compensatory training to cope with and or to overcome the disability.

Table #1 identifies the twelve service components of comprehensive medical rehabilitation as classified by the National Association of Rehabilitation Facilities. What is striking is that most skilled nursing facilities already are obligated to provide or to make arrangement for the provision of these services. The key point being that skilled nursing facilities are already positioned to strengthen rehabilitation services to meet patients needs.

As Table #2 illustrates, of the 1.4 million dependent elderly living in nursing homes, about 92% of these elderly residents had one or more limitations in an activity of daily living (limitations in bathing, dressing, using the toilet, getting in out of bed or chair, continence, and/or eating). Approximately half were very dependent with five or six ADL dependencies.

Three factors influence the translation of the documented functional impairments of the nursing home population into the demand for rehabilitation services:

o facility capability:

With few exceptions, the capability of nursing home facilities to attend to the identified level of dependency of nursing home residents has been under developed. Because of perverted reimbursement incentives and significant shortages of professionals, few facilities have had an opportunity to develop services.

Most facilities contract out for their speech-language, occupational and physical therapy services. NovaCare is the only national contract rehabilitation supplier of sufficient scale to attract, retain, supervise and provide quality assurance support to clinical professionals from all three disciplines. This integrated management of therapy services provides a level of cooperative, comprehensive care, heretofore available only in acute care and rehabilitation hospitals. For our nursing home customers, this focused commitment provides a single contract for resolving service needs, a single standard for documentation and a core of professionals all delivering the same message to nursing and support staff.

o coverage restrictions:

Most third party payers, including Medicare and Medicaid, restrict coverage for rehabilitation services to patients exhibiting strong rehabilitative potential. Over 60% of nursing home residents with functional impairments exhibit poor or no rehabilitation potential, and, therefore, services are seldom made available.

o reimbursement limitations:

While Medicare is a minor payer for most nursing home care, it is the primary and most consistent payer for rehabilitation services in the SNF setting. "Skilled Rehabilitative Services" is one of the qualifying criteria for Part A coverage. The patients must be eligible, have their physician order the service, have rehabilitative potential and demonstrate progress during treatment. Qualifying services can also be provided under Part B subject to copayment requirements. A facility can provide services through its own staffing or under arrangement with a contractor. Non-certified facilities can receive services under arrangement with a Medicare certified rehabilitation agency.

The repeal of catastrophic coverage is a significant disincentive for facilities developing rehabilitation services. The legislative retreat narrows the coverage, increases the out-of-pocket costs to beneficiaries, places the facility at greater risk for default on patient debts and limits the reasons for upgrading facilities to care for heavier care patients.

Medicaid is a minor purchaser of rehabilitation services. As recent HHS sponsored research concludes:

> Most public funding methods for long term care do not adequately match payment rates with patient need for services....Even nursing home case-mix payment systems, however, do not currently provide the proper incentives to match rehabilitation therapy resources to a patient's needs." ("Nursing Home Reimbursement and the Allocation of Rehabilitation Therapy Resources," _Health Services Research_, October, 1988).

Few nursing facilities have programs advanced enough to attract private third party insured reimbursed patients.

II. Public Program Enhancements to Strengthen Rehabilitation Services Delivery:

As the Commission reviews recommendations for enhancing long term care services, it should include a focus on serving the rehabilitation needs of that population. The following are a few recommendations which should be considered to assure that public programs are responsible in matching resources to expectations:

1. Unbundle Ancillary Therapy Reimbursement:

As research from the National Center for Health Care Research indicates, the trend toward bundled payment of long term care understates therapy cost. At present, it is impossible to predict utilization and/or to equate reimbursement and outcome. In order to preserve appropriate service delivery, maintain quality service, and provide adequate reimbursement therapies need to be preserved as an individually determined ancillary service. This preserves the status-quo basing services on the facts and circumstances of the condition of the beneficiary.

2. Reform of Medicare Reimbursement for Therapy Services:

The Medicare statute restricts reimbursement for therapy services to a salary equivalency format. Chapter 14 of the Medicare Provider Reimbursement Manual implements this directive. The salary equivalency format understates delivery costs, neglects differences in quality of service and differences in types of patients served. Moreover, given the dramatic shortages within the professional labor market, the format understates base labor costs. The Medicare reimbursement methodology for therapy services should be altered to reflect these market conditions while building in incentives for efficiencies. At a minimum, salary equivalency guidelines issued by HCFA should be rebased to reflect current market conditions.

3. The Goal of Therapy Services Coverage should be to Maximizing Individual Functioning:

The Medicare statute restricts patient selection to a very narrow range of patients, e.g., those with recuperative potential. Thus, therapy services are not reimbursed for Alzheimer patients, individuals with neurological disorders, cancer patients etc, typical patients seen in a long term care setting. The coverage criteria should be services which maximize individual function.

4. Expand Medicare Coverage for Audiology Services and Related Speech-Language Services:

Current law provides very narrowly defined audiology services. Hearings aids, and training for use of such prosthetics, should be a covered service. Short of expanding Medicare to cover hearing aids, there is a spectrum of corrective communications skills which should be permitted under the statute. These audiology services can be tied to the coverage statement of maximizing individual functioning. Additional enhancements should include clarifying coverage for aural rehabilitation and coverage for new communications technology. Aural rehabilitation is patient training in lip reading performed by a Speech-Language Pathologist and/or an Audiologist. Medical review guidelines developed by HCFA do not clarify coverage. Aural rehabilitation treatments significantly enhance the quality of life for patients with communications disorders, and, with proper treatment can reduce the number of mis-diagnosed Alzheimer patients. New technologically advanced devises are being developed such as communication boards, which, with proper training, can permanently replace the functions of the vocal cords for those individuals incapable of speaking. Such services would be a small, but meaningful and cost beneficial program enhancement.

5. Mandatory State Buy-In for all Medicare coverage under State Medicaid Plan without exception or limitation:

In spite of the clear statutory direction set forth in the Medicare Catastrophic Coverage Act, several states continue to restrict their buy-in to services covered under their Medicaid plans. Texas, for instance, stopped paying co-insurance for outpatient Part B therapy services over two years ago, without altering their needs allowance calculations for determining indigence. The Commission must underscore the importance of the buy-in provisions to indigent beneficiaries and press for mandated performance.

6. Imposition of a specific Redress Mechanism, complete with financial sanctions, on intermediaries and carriers:

The balance in Medicare is highly tilted to paper compliance, rather than the actual provision of care. Providers and suppliers must have a fair redress mechanism (beyond individual case appeal) to challenge fiscal intermediaries and carriers who (i) continually mis-interpret Medicare statute, (ii) neglect the procedural requirements in making audit determinations, (iii) force challenges to the PRRB on issues which should have been settled at the intermediary level and (iv) exhibit a pattern of intimidation of providers/vendors in their audit and claims management functions. While HCFA performance evaluations of intermediaries have improved responsiveness, there is neither an ombudsman for addressing grievances nor am office for securing advisory opinions to assure that business decisions are in compliance. Whatever broad delivery system the Commission proposes, it should recognize the need for a fair redress mechanism.

7. Payment reforms arresting cash flow problems of Rehabilitation Agencies:

Within the framework of the recent statutory requirements on payment, HCFA should provide a "hardship" relief mechanism for smaller agencies which can demonstrate undue cash flow problems resulting from the delayed payment of claims. Such an approach does not undermine the statutory/budgetary savings objectives, but provides relief for smaller agencies, especially smaller rehabilitation and home care agencies.

8. Restrictions on the volume of unauthorized and incidental paperwork, especially billing questionnaires which are being imposed by intermediaries and carriers:

There is a shifting of the administrative responsibility for managing healthcare from the bureaucracy to the provider. In spite of the paperwork reduction initiatives, intermediaries and carriers are proliferating the amount of paper which is required. The most recent abuse in through billing questionnaires, which are often summary statements of information already available to the intermediary. HCFA must get this under control, if it is to contain administrative costs of the provision of service.

9. Consistency of State/Regional Office policy directives on certification and survey:

No two HCFA regions, working from the same statute and manuals, have the same interpretation. This confuses providers and the states. For example, Region V believes in controlling the provision of care to the extent that genuine provider efforts toward efficiencies are thwarted. Attention must be given to policy implementation if there is an expectation of conformity in execution.

10. Stable Business Climate:

The public sector is a cruel dictator at the point of service delivery. Providers are forced to adapt to endless swings in policy direction and countless exercises which start and stop without reason. If the goal is to attract the best providers, assure the highest professional care and achieve efficient, economical delivery, then government must stabilize its decision process. The inconsistent execution of the extended care benefit under Medicare is the primary reason why nursing homes have not developed their rehabilitation potential. There is a crying need for greater stability.

III. Summary:

Historically, the nursing home industry has been a "residual provider", picking up responsibilities for those patients cast off from other sector of the health care system. The opportunities for providers in medical rehabilitation are a spin-off from the acute hospital prospective payment system - - patients are discharged more quickly from the hospital, enabling the nursing home to be the focus for rehabilitative services.

The Commission should focus a portion of its efforts at assessing how long term care providers can best enhance rehabilitation services to meet patient needs. As suggested in this testimony, nursing homes, in particular, are well positioned to expand their focus. The Commission has the unique opportunity to help shape those developments and to make recommendations on improving the allocation of resources to achieve strong medical rehabilitation in the long term care setting.

Thank you.

TABLE #1: REHABILITATION SERVICES

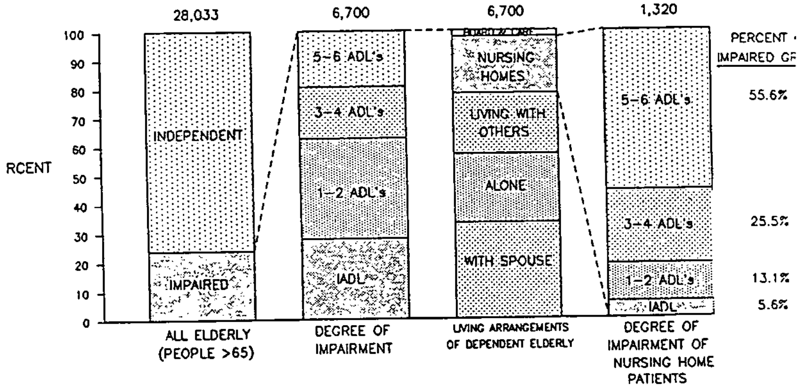
- physical therapy
- occupational therapy
- speech-language pathology
- respiratory therapy
- prosthetics
- physician services
- orthotics
- social services
- psychological services
- rehabilitative nursing
- drugs and biological
- supplies, appliances & equipment

Source: Batavia, Andrew, The Payors of Medical Rehabilitation: Eligibility, Coverage and Payment Policies, NARF, 1989.

Table #2:

OCCUPANCY BY ELDERLY OF NURSING HOMES

BY DEGREE OF IMPAIRMENT
(1985)



SOURCES: NATIONAL LONG TERM CARE SURVEY; NATIONAL NURSING HOME SURVEY; HCFA; SCANLON ET AL

ActionAIDS

Item 7

ActionAIDS
1216 Arch Street
Philadelphia PA 19107-9749
Telephone 215 981-0088

TESTIMONY OF ENNES LITTRELL, EXECUTIVE DIRECTOR OF ActionAIDS, PHILADELPHIA

TO THE PEPPER COMMISSION: NOVEMBER 13, 1989

Members of the Pepper Commission:

Good afternoon. My name is Ennes Littrell and I am the Executive Director of ActionAIDS, a volunteer-based, nonprofit organization that provides a broad range of direct services to over 400 people living with AIDS and active HIV disease in Philadelphia.

ActionAIDS' services are centrally coordinated by professional case managers, who individually assist our clients by negotiating social services and other systems, and working to ensure that clients receive the highest level of care and benefits available to them. Having been first awarded the Philadelphia Health Department case management contract for AIDS in 1988, we are now the case managers of record for people with AIDS in Philadelphia.

As you prepare your recommendations to Congress on national health care access and long-term care, I urge you to consider carefully the needs of people with AIDS. In terms of the dollars needed for their care, this group is quickly becoming the largest single subgroup of medically indigent people in our population. The national average in annual medical costs alone is now $20,000 to $30,000 for each American with AIDS.

It is self-evident that any overall care plan that does <u>not</u> include specific measures to contain the fiscal costs of AIDS in a comprehensive, compassionate way will inevitably fail in its misison as long as this epidemic is running rampant.

There was a time, of course, when long-term care was not an issue for people with AIDS and HIV infection. In the early days of this health crisis clients who lasted six months were considered "long-term survivors." Today, thanks to the increasing availability of effective drug treatments, we are hearing tentative murmers from the medical community that AIDS and HIV infection soon may be classified as a chronic, treatable illness, not a death sentence.

At ActionAIDS, our case managers, client advocates and a huge corps of community volunteers are providing thousands of hours of service annually to people living with AIDS and have seen more suffering and death in the last few years than any of us expected to see in one lifetime. We are cautiously optomistic about the recent medical trends that are making it possible for people to live for many years with medically treated HIV infection. Already, the constantly shifting terminology of the epidemic is again changing for the better: once victims, then patients, a majority of people with AIDS now prefer to be called people <u>living</u> with AIDS.

This good news, however, has ramifications that almost as frightening for our health care system as the daily death counts. Simply put, we are at present ill-prepared to support medically the people with AIDS who keep on living. We can no longer rely on rapid turnover to supply us with the necessary case managers, hospital beds and private treatment facilities this crisis demands. The rhythm of the AIDS epidemic has changed. And while we rejoice in anything that stems the tide of deaths, we have not yet developed a federal plan that will enable us to respond effectively to the needs of those living with AIDS -- whose numbers are growing now even more rapidly.

Since 1981, when AIDS cases were first monitored by the Centers for Disease Control in Atlanta, the American medical community has had to absorb approximately 109,000 sick people for whom it was utterly unprepared. That's over 100,000 people whose needs are directly competing for the resources previously allocated to the elderly, the injured and those people suffering from the relatively predictable caseloads of such chronic illnesses as cancer and heart disease. To say the least, the American medical community--and the government structures that help support it--were caught off guard.

As we prepare to enter the '90s, we can't afford to be caught unprepared again. This time, at least, we have the luxury of planning on the basis of some hard numbers.

Right now, we know that the number of people living with AIDS in the United States doubles every 22 months. According to the CDC, 44,318 Americans were living with full-blown AIDS at the end of September. By July of 1991, this will have doubled to 88,636 and by May of 1993 to 177,272. By the end of 1996, over 700,000 men, women and children will be living with AIDS in the U.S. Millions more, having already been exposed to HIV, will stand a high probability of developing symptoms. The Public Health Service estimates that 1.4 million Americans have been exposed to HIV already, so one can only imagine the massiveness of this figure by 1996.

What this means for us as taxpayers and as consumers of medical services is equally overwhelming. The U.S. General Accounting Office has documented extensively the fact that Medicaid is the leading payer for AIDS services, covering as many as 40% of all people with AIDS. In Philadelphia, the Delaware Valley Hospital Council has documented the financial hardship that inadequate levels of Medicaid reimbursement is now causing hospitals. In 1988, only $4500 of the $8000 cost of an average AIDS hospital admission was reimbursed by Medicaid, causing a $3500 shortfall per Medicaid admission. How long can we expect our hospitals to absorb these losses? And for how long can we assume that these funding losses will not affect the level of care that our hospitals are able to provide to the general population?

In drafting any comprehensive health care recommendations for this new decade, planning for AIDS is critical. It is a new epidemic and one that is expanding more rapidly than any of us could have imagined. One cannot begin to plan accurately for the future of long-term health care in this country without first planning the future of AIDS care.

At ActionAIDS, we have spent years working closely with people with AIDS in Philadelphia, which now has the ninth highest incidence of AIDS in the nation. We can say with absolute certainty that one thing that most people with AIDS emphatically want is to be able to stay in their own homes and to receive medical care with as much autonomy and as little disruption as possible. This kind of care emphasizes mutually negotiated and careful case management, nursing and day care alternatives based in the home, and a partnership between health care institutions and community-based support systems.

Fortunately for all of us as taxpayers, this kind of care is least expensive. It is, in fact, the only model I know of that could enable us to stretch our limited resources sufficiently to provide humane, medically adequate longterm care to the huge numbers of people with AIDS that we will have in our midst in the very near future.

Let me give you a concrete example of the kinds of systematic changes and cost savings I'm talking about. California is one of the few states that now places emphatic funding priority on supporting home based (instead of hospital based) health care models for people with AIDS. They have improved viability of home-based care by increasing public funding for home attendant and home health nursing services, bolstering the availability of nursing home and hospice services, providing massive support for community based organizations that serve people with AIDS in their homes and making full use of the Medicaid waiver option for AIDS services.

In terms of cost, they have demonstrated concretely the results of these initiatives. In San Francisco, for example, the average medical costs generated per person with AIDS per year has dropped to $18,168. These data are provided by a recent study entitles "AIDS in California", published by the California State Department of Health. Contrast that number to the General Accounting Office's estimation that the direct medical costs nationally average $20,000 per person with AIDS per year. You will immediately see that these systematic improvements in care delivery have resulted in an average savings of $1832 per person per year.

While that figure alone may not seem dramatic, it becomes so when multiplied by the 44,318 people living with AIDS this year and the 700,000 people that we must expect to be living with AIDS in the U.S. seven years from now. As you see, we would stand to save nearly $81 million ($81,190,576) in direct medical costs this year and nearly $1.3 billion ($1,282,400,000) in 1996 alone, just to use 1989 and 1996 as examples.

Former Surgeon General Koop has advised us that a vaccine against AIDS will most probably not be available before the turn of the century. Tragically, we must anticipate that the number of people living with AIDS, and the corresponding cost of their health care, will double twice more before the end of the year 2000 if current epidemiological trends continue. Although this escalation seems incomprehensible, it must be remembered that at least 1.4 million Americans are estimated to be HIV positive <u>today</u> and that the virus waits out a silent latency period averaging between 7 and 15 years before becoming active.

This redoubling will result in at least 2,836,352 people living with AIDS in the year 2000. We could save $5.2 billion ($5,195,552,000) in that one year by doing no more than implementing now the limited parameters of the model described above.

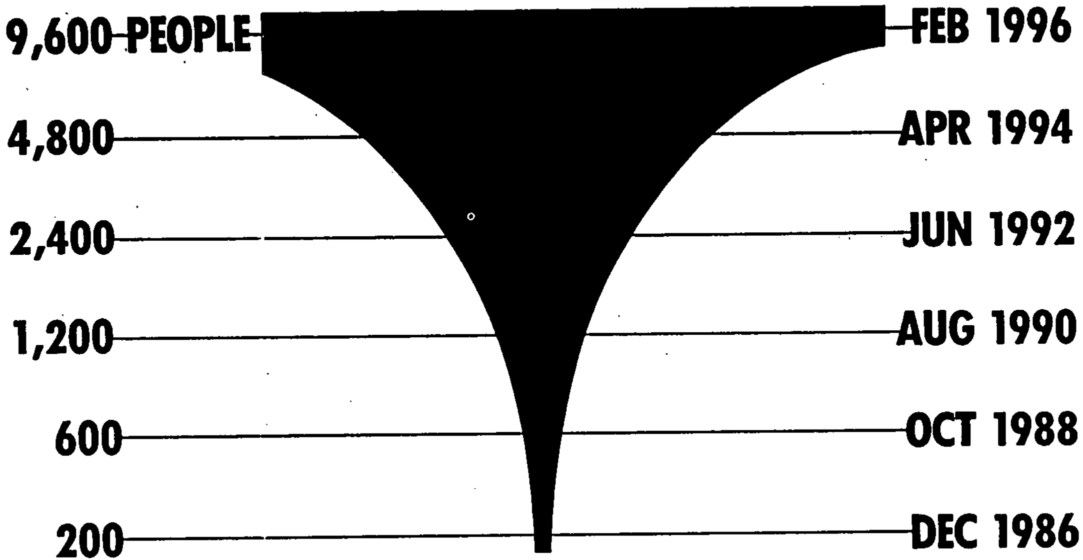
Clearly, we are talking about millions of Americans living with AIDS in the next decade and billions of dollars that can be <u>saved</u> by instituting strong national funding for the kind of care that people with AIDS really want. And you, as members of the Pepper Commission, have the power to recommend this humane, compassionate, cost-containing strategy to Congress.

Surely this is a case of being able to do good and do well, simultaniously. Surely this is the answer to pressing question of how to keep our fragile medical system from collapsing under the unexpected weight of the AIDS epidemic.

In the early days of the AIDS epidemic, the United States could claim ignorance for its failure to respond effectively to this health crisis. But those days have passed. Like a storm gathering force as it moves up a shoreline, the AIDS epidemic is broadening its sweep, claiming more lives and wreaking more devastation than was once imaginable. In its wake, this storm will leave us with millions of people whose very survival will depend on a national health care structure designed to accomodate their tremendous needs.

It is beyond our power to rescind the thousands of transmissions now waiting out the deadly, silent incubation period. But it's not beyond our power to decide <u>today</u> how we intend to cope with the staggering health care challenges of the 1990s and beyond. Please join me in asking Congress to provide the health care structures necessary to care for our families and friends who are living with AIDS. Thank you.

People Living with AIDS in Philadelphia



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Item 8

celebrating 20 years of advocacy and service **nim**

November 22, 1989

Honorable John Heinz
SR 277 Russell
Senate Office Building
Washington, DC 20510-3801

Dear Senator Heinz,

The Long Term Care Connection of the Northwest Interfaith Movement (NIM) has been involved in a broad range of projects and issues related to older adults for more than a decade. We provide complaint resolution and volunteer visitation to nursing home residents in Northwest and Northeast Philadelphia and to boarding home residents throughout Philadelphia through the Philadelphia Long Term Care Ombudsman Program. We brought both boarding and nursing home residents to the Pepper Commission Hearing on Monday, November 13th.

We did not have the opportunity to testify at the hearing, but were pleased that the points we feel are most important were brought to the Commission's attention. We agree that senior citizens are not the only consumers of long term care, that all families will feel the need for long term care coverage, and that long term care coverage should be part of a National Health Policy, funded through general revenues.

An additional point we feel compelled to raise concerns the issue of liability. Right now, in Pennsylvania, a facility which does not forcibly provide food and water to a resident is risking a charge of murder. If a competent resident of a nursing home refuses food and water, the nursing home sends the resident to a hospital, where a feeding tube is inserted, because the facility's need to avoid liability is greater than the need to honor the resident's wish to die without medical intervention. Allowing people to refuse medical treatment, even when that refusal means death, in effect means legalizing living wills or encouraging the use of durable powers of attorney.

This is not an easy concept to incorporate into a long term care policy. However, an individual's right to self-determination at all stages of the life cycle should be part of a system which allows people at the end of their lives to refuse medical treatment.

Thank you for your consideration of our point of view.

Sincerely,

Kristen Van Orden
Long Term Care Ombudsman

Mary Gibbs, President
Legislative Committee
Coalition of Resident Councils

NORTHWEST INTERFAITH MOVEMENT
Greene and Westview • Philadelphia, PA 19119
(215) 843-5600

celebrating 20 years
of advocacy and service nim

November 13, 1989

To: Members of the Pepper Commission

From: Mary J. Fallon, Director
Long Term Care Connection

Attached is testimony focusing on the Long Term Care component of a health care system, which we developed in concert with our Resident Council members. Both Mary Gibbs, Chair of our Coalition of Resident Councils Legislative Committee, and Susan Toomey, Chair-elect of Our Lady of Holy Souls Boarding Home Residents Council, were instrumental in providing feedback and sharing concerns. Long Term Care staffers Kristen Van Orden and Gregory Tisdale may be contacted if the Commission needs further information or wishes to have more direct contact with residents. Either may be reached at 843-0304 weekdays, between 9-4:30.

Testimony of the Long Term Care Connection
Northwest Interfaith Movement

Submitted to the Pepper Commission
November 13, 1989

The Long Term Care Connection of the Northwest Interfaith Movement (NIM) has been involved in a broad range of issues related to older adults for more than a decade. We provide complaint resolution and volunteer visitation to nursing home residents in Northwest and Northeast Philadelphia through the Philadelphia Long Term Care Ombudsman Program. We also provide ombudsman program services to residents of licensed personal care boarding homes citywide. We serve as an impartial source of information about nursing homes and the nursing home admission process for consumers, and produced Nursing Homes in Philadelphia: A Directory and Consumer Guide, a 140 page volume profiling local nursing homes and factors to consider when seeking a nursing home placement. In addition, and perhaps most importantly, we work to empower residents of long term care facilities by organizing and coordinating Resident Councils in both nursing and boarding homes. Our Coalition of Resident Councils represents nearly 5,000 Philadelphia nursing home residents.

As resident advocates, we are often the first to respond to complaints and other problems which residents face on a daily basis. Residents are constantly faced with issues of physical and verbal abuse, financial exploitation, unclean and/or unsafe living conditions, intimidation, and complete disenfranchisement from the decision making process that impacts their lives.

Our experience working directly with and on behalf of residents has brought home to us quite forcefully the need to include long term care in any discussion of a comprehensive health care system. To prepare this testimony, we met with residents in order to accurately reflect their experiences as consumers of long term care services. The most critical issues are addressed below:

1. The needs of consumers of long term care services should be considered by the Commission in the broadest terms, from in-home services to Senior Centers, from Adult Day Care to Personal Care, up through and including skilled care. Such a broad view will assure that a comprehensive National Health Care Policy is developed.

2. Ideas and opinions from consumers of long term care services must be solicited in more creative ways. Typically, the format of public hearings is not conducive to protecting residents' privacy, nor to accommodating residents' varying degrees of functional limitations.

3. A comprehensive health care system must be client/resident-centered. Currently, the system is geared to fitting consumers into particular slots or models. Models must be responsive to consumers as human beings, not as collections of symptoms.

4. More dollars must be targeted to long term care. Some of the more problematic areas include:

   a. In the 1987 Omnibus Budget Reconciliation Act (OBRA), Congress mandated quality of life in long term care facilities but failed to properly fund its implementation. Such a failure to allocate funds impedes the provision of high quality care and, by so doing, reduces the quality of life. Insufficient attention has been paid to the fiscal environment within which providers are forced to operate.

   b. Quality of life in nursing homes is related to the resources available in terms of both personnel and dollars. Money is needed to address the problems of a tight labor market and the resulting increases in labor costs. Dollars must be allocated for training additional health care professionals. Dollars are needed for program structure and implementation. Providers must be assured timely reimbursement by States.

   c. Increasing numbers of licensed personal care boarding home providers are unable to continue providing quality care because of the escalating costs to operate a home, and the fact that many, sometimes most of their residents are on a fixed income (Social Security, Supplemental Security Income, General Assistance). Providers claim that residents on these fixed incomes can no longer cover the rising costs of room, board and adequate personal care services. Increasingly providers are reluctant to admit residents on these fixed incomes. Many SSI recipients are ending up in unlicensed or commercial boarding homes--some are going homeless.

      Federal dollars are needed to provide additional funds to supplement what states are doing to address this issue. Providers must receive necessary increases in order to provide adequate services to boarding home residents.

   d. National standards and regulatory oversight of the boarding home industry are critical developments that must emerge in the immediate future. In Pennsylvania, state regulations allow boarding homes with three or fewer personal care residents to operate without any state regulations or licensing procedures; these types of homes outnumber licensed personal care homes almost two to one. There is virtually no oversight of these homes. At present, there are no assurances for the well being of residents of unlicensed homes. National legislation regulating boarding homes can create a uniform national standard to protect residents and insure their safety and well being. Any such legislation must be adequately funded.

5. A careful exploration of regulating profits of long term care providers must be completed. Just as public utilities profits are regulated, the long term care industry may be appropriate for such oversight.

6. Access by poor and near-poor consumers to health care and long term care must be assured. Availability of private insurance must be enhanced. The Medicaid system must not only function as a long term care insurance policy for the middle class. Providers must shoulder their fair share of caring for the poor and near poor who may qualify for Medicaid upon admission to a long term care facility.

7. Finally, residents of long term care facilities must be encouraged and assisted to express their concerns and participate in decision-making processes that impact their lives. Many residents experience a great sense of isolation and confusion, leading to feelings of powerlessness over their own lives. This powerlessness is very real. There is virtually no circulation among residents of information on resident rights or other available resources. This vacuum keeps them unaware of their rights and the possible actions they may be able to take to influence decisions which affect their lives. Those who may have ideas about what they can do to improve their situation are often frustrated that they have no collective voice or avenue through which to act.

   We believe that the development of Long Term Care Resident Councils locally, regionally, statewide and nationally, can provide residents with a vehicle to voice their concerns and build a cohesive group who together can take action that will improve their lives. These formalized groups empower residents to become more assertive, self-confident and independent, thus impacting on institutions or structures such as social service agencies, provider associations, legislative bodies, and the community at-large.

We appreciate the magnitude of the task the Commission is tackling. Thank you for the opportunity to present our point of view. We stand ready to assist the Commission in any way possible.

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